TB/MDR-TB
Advocacy Tool Kit

advocacypartnership

Acknowledgements

Preface

The world of communication and advocacy is changing rapidly. In the space of just ten years we have been given access, literally at our fingertips, to brand new and amazing technology that allows us to talk to a worldwide audience by the simple click of a mouse, or the touch of a mobile phone key pad. Social networking is today the preferred way of communicating among the youngest with an enormous potential to reach out in every part of the globe.

Never before have so many opportunities to advocate been so easily accessible and by millions of ordinary people. This progress shows no sign of slowing. New technology is still in its infancy. And as technology marches forward and develops so too should advocacy, especially TB advocacy, a disease that is widely considered no longer a problem.

TB advocates can champion many great achievements. We have seen vast improvements in TB treatment and care, we are on target to reach the 2015 Millennium Development Goal related to TB, a non-ambitious target of making incidence decline and yet so significant after decades of increase, and the TB death rate has fallen by 35% since 1990. Furthermore 41 million people have been successfully treated since 1995, and up to 6 million lives have been saved through DOTS and the Stop TB Strategy.

But it still remains an unfortunate fact that not everyone in the world who needs TB care is able to get it. A third of people with TB are likely not reached with accurate diagnosis and appropriate care – that's more than three million people each year.

Many of them are in marginalized groups – slum dwellers, migrant workers and drug-users, among others. In the 21st century, no one should die from TB, a curable disease.

The challenges around HIV-associated TB and drug-resistant forms of TB such as multidrug-resistant TB (MDR-TB) and extensively drug-resistant TB (XDR-TB) continue to test TB programme managers. The result is that calls for action from advocates, demanding that their governments match commitments on paper with extra funding, can sound hollow.

But, with the guidance found in this tool kit – and by sharing successful strategies between advocacy networks – I do hope that commitment for resources and implementation of measures to address all forms of TB can be secured.

Every TB advocate can learn something from this toolkit that I hope could lead to an innovative and more effective message to perhaps a new audience. It may be a new technique in delivery, or the discovery of an untapped network eager to learn more about how they could become engaged in the global fight against TB, or yet other ways.

It is only through strong advocacy, supported by state-of-the-art skills, can our calls for action penetrate beyond the surface, and help achieve the desired goal of a world that is free of tuberculosis.

Dr Mario Raviglione
Director, Stop TB Department
World Health Organization

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Introduction

Advocacy encompasses the skills and activities employed by constituency groups to bring about change. It is an important part of the work of civil society as both 'influencer' and 'watchdog', effecting change in programmes and policy and ensuring governments and stakeholders keep to their word.

This tool kit is the result of years of experience of TB advocacy in the UK and abroad, lessons we have learned from advocacy trainings, and desk-review. It has been put together by Sheila Davie, former Executive Director of RESULTS UK and Renato Pinto, formerly of TB Alert and Senior Adviser, Technical Co-operation Unit (Global Fund). Becky Owens, a media consultant, contributed significantly to the media sections.

It reflects our personal experience of TB advocacy and that of many partners and colleagues with whom we have worked over the years. We thank and acknowledge all those we have worked with and in particular RESULTS UK, RESULTS US, The ACTION Project, Stop TB Partnership and World Health Organization Stop TB Department, TB activists Winstone Zulu and Lucy Chesire and the UK Coalition to Stop TB.

The purpose of the tool kit is to complement the advocacy trainings being delivered by the Advocacy Partnership and be a resource for future in-country trainings.

It was created at the request of participants of the Advocacy Partnership trainings and from others participating in needs assessment studies. Many people recognised the need to package the many resources already available, but not necessarily accessible to everyone.

The audience for this tool kit are all TB advocates and stakeholders, nurses, community workers, people and communities infected and affected by TB, and HIV/AIDS activists.

We hope it will be a useful resource to help strengthen the advocacy skills of TB stakeholders and their ability to design and deliver campaigns that can be integrated into and enhance other TB programme work. However, the tool kit is adaptable and applicable to other issues.

Although in many environments advocacy is not 'professionalised' and any one organisation may not have a person solely dedicated to advocacy work, it is still essential to programme work and to achieving overarching objectives. Many working in the TB field know of its important role in strengthening and invigorating country-responses to TB, in particular MDR-TB and TB/HIV. However, there is also a need to incorporate advocacy right across all TB work.

Advocacy has a key role to play in raising the sense of emergency in the context of MDR-TB, to increase demand for services to tackle TB and MDR-TB (more effective diagnostics, second-line drugs, infection control measures etc.), to ensure respect for human rights in the context of MDR-TB and more generally to accelerate action to deliver the Global Plan to Stop TB.

We trust it will become a useful resource for your work and we welcome your feedback.

Section 1

What is advocacy?

Photo courtesy of
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What is advocacy?

"Advocacy is a process to bring about change in the policies, laws and practices of influential individuals, groups and institutions."[1]

Advocacy is a process of change – a series of activities linked to a defined goal – and not just a one-off event. To be successful, advocates need to be clear from the beginning what change they want to bring about, what needs to occur to make that change happen, who (which key people) can make that change take place, and how they as advocates can work to influence those key people.

Advocacy is also:
- Just one approach
- A tool for increasing effectiveness of other approaches
- Has differing forms and timeframes
- Can be done alone or with others
- Can be reactive or proactive

We all do it!

Advocacy work and programme delivery are parallel processes. This can be demonstrated well using railway lines as an analogy. Two rail lines: one programme delivery, the other advocacy – making change happen.

Both are needed, they depend on each other and one without the other cannot really deliver. One complements the other.
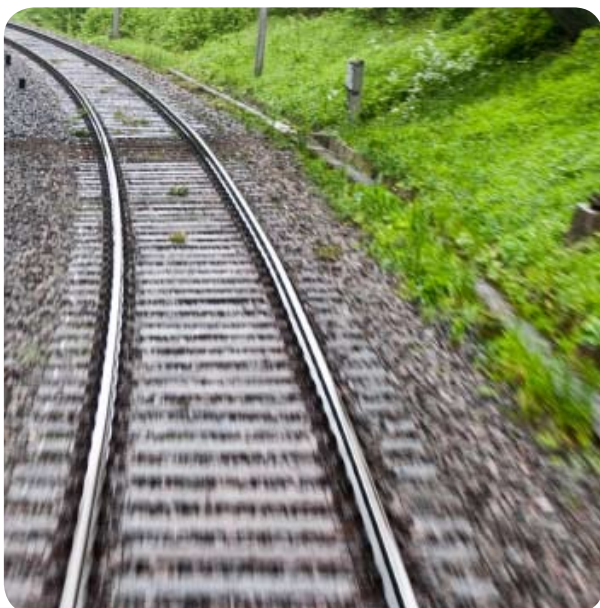
Photo: © iStockPhoto.com / Adrian Assalve

Definitions: Advocacy? Communication? Social Mobilisation?

There is no single definition of advocacy. But we can get behind the motivating idea of what advocacy is in the definition below.

Advocacy aims to secure financial resources and change policies, guidelines or procedures through influencing of stakeholders such as politicians, decision-makers and journalists.

Communication seeks to increase awareness, influence social norms, bring about behavioural change by targeting individuals and 'sub-groups' in the public domain and improving interpersonal communication and counselling between people with TB, their families and providers.

Social mobilization aims to change norms, improve services and expand community support. It influences communities to identify and address problems.

How advocacy complements and enhances other TB work

Advocacy is only one approach to influencing TB prevention, care, impact and policy work. Other approaches include community mobilisation, education, public health measures, good medical services and community support.

By gaining the support of people in power and changing the social environment in which this work takes place, advocacy can enhance these other approaches, making them more effective.

Almost all non-government organisations (NGOs) have experience of doing advocacy – even if they do not realise it, or do not use the word 'advocacy'.

It is not a new or unique concept, neither is it exclusively a 'western' or Anglo-Saxon model. Individuals and groups have always tried to influence people in power, in their private lives and as part of their work.

Advocacy can take many forms. In relation to TB, it could for example be: a coalition of civil society organisations (CSOs) holding a press conference or jointly signing an open letter; a meeting with a country's President; or a drama about rights performed for key decision-makers by actors living with TB.

Advocacy can be written, spoken, sung or acted. It can also vary in the time it takes – from a few minutes to several years.

We can do advocacy on our own or with others. It is possible to advocate for other people or for ourselves.

Some of the most powerful advocacy is led by people directly affected by the problem or issue.

Advocacy and ACSM – What's the difference?

To understand advocacy as a means of persuading influential people to change, it is important to make a distinction between advocacy and associated activities. ACSM is a term used frequently by the TB community. It stands for Advocacy, Communication and Social Mobilisation. Another term is IEC which stands for Information, Education and Communication.

IEC and SM are more about working with the general public or specific 'focus' groups of people. IEC's main objective is to raise awareness and change behaviour. The main objective of SM or community mobilisation is to build a community's capacity to identify its needs and take action to fulfil them. Confusion reigns between these activities because IEC and SM also involve influencing, persuading and mobilising people into action – many of the key activities we associate with advocacy.

There may well be campaigns where top-level Advocacy combines with IEC and SM. The former (Advocacy) to influence policy and decision-makers 'top-down' and the latter (IEC and SM) to build a bottom-up 'groundswell' of opinion in order to influence policy and decision-makers through public opinion and action.

However the objective of this tool kit is to address how we can change TB policy and influence people who have the power to make that change. Consequently our focus is on advocacy and related activities.

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Advocacy opportunities

To effectively identify opportunities for influencing funding and the programme and policy process, advocates need first to understand the usual rules and procedures a country uses to make funding, programme and policy decisions.

These may be at the national level, where discussions are focused on broad policy issues and official national policies, or at the operational level, where specific resource allocation and service delivery guidelines are formulated. They can be 'reactive', which requires moving fast when a local, national or international event provides an opportunity for TB advocacy. Or they may be 'proactive', which requires a strategy and planning for the future in order to have maximum impact in what you are saying and on the people you are trying to influence.

Reactive advocacy

Advocacy work can be forced on us. The problem or issue is already there, and advocacy is needed to reduce the problem. This is 'reactive' advocacy and an example is an action by the Kenya AIDS NGOs Consortium (KANCO)[2] in response to a suspension of a grant from The Global Fund to Fight AIDS, Tuberculosis and Malaria (GFATM). *See Box Reactive advocacy*: *CSO responds to Global Fund issues in Kenya*. Though not entirely successful (in that Global Fund money was not all disbursed), this advocacy campaign called on support from UK and US activists and drew much needed attention to the failure of the Kenyan government to disburse Global Fund resources so that suspension of the grant was lifted. This advocacy laid the foundation for successful coalition advocacy work in the future.

Photo courtesy of Renato Pinto

↘ Photo: **TB advocates meet to discuss advocacy tactics at the IUATLD meeting in Paris.**

Reactive advocacy: CSO responds to Global Fund issues in Kenya

Background

As of 2010, Kenya had been successful in applying for four TB grants from the GFATM. These include Rounds 2, 5, 6 and 9. Round 9, amounting to US$45 million, was approved in 2009. However this grant was rated category 2B and would only be implemented based on the availability of funding. Currently the fund is awaiting signature of the Principal Recipient, AMREF in this case.

Problem statement

For Round 2, Kenya qualified for US$8,761,404 (equal to Ksh 657 million). It was to be disbursed in two phases, phase 1 being US$4,928,733, and phase 2 US$3,832,672. When the Global Fund was dissatisfied with the performance of the grant, it was suspended.

Strategies employed to try to lift the TB suspension

Document review and consultations on the Hatib and Olum reports were prepared by consultants to analyse the problem; assess implementation challenges; review findings, and establish a way forward. Activities included:

- Networking meetings with civil society organisations to develop a common position and response to the Hatib and Olum reports.
- Creation of a loose coalition on AIDS, TB and malaria, critical in advancing the advocacy for TB.
- Review of Country Coordinating Mechanism (CCM) membership and steps take to ensure transparent election of different constituencies on the CCM.
- External advocacy by other advocacy groups in the US, UK among others.
- Consistent outreach to the board members of the Global Fund to ensure that we had allies in ensuring that the suspension was lifted.
- Communication with the Portfolio Manager to help iron out the challenges in the whole process.
- Generation of media articles on the situation on why commitment was needed from the Government to account for the money and implement support.
- Holding of press conferences by civil society.
- Meetings with a delegation from the Global Fund to include Deputy Director, GFATM Helen Evans, East Africa Manager, GFATM Linden Morrison, and Portfolio Manager Kenya Victor Bampoe.

Outcome of all the efforts

- The TB grant suspension was lifted conditionally and the country was given nine conditions.
- The TB Round 2 grant came to an end on 30 October 2008 with only US$3,299,522 (equal to Ksh 247 million) having been disbursed.
- This means that the country lost Ksh 409 million due to lack of accountability and slow disbursement. The Ministry of Finance also did not account for a significant portion of this money.

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Proactive advocacy

At other times it is possible to plan for the future, to 'set the agenda' and use advocacy to create a positive environment or prevent a problem before it happens. This is 'proactive' advocacy.

An example of this is CSO attendance at a meeting on TB in Berlin in 2007 co-organised by the European Commission Directorate-General for Health and Consumers (EC-SANCO), European Centre for Disease Prevention and Control (ECDC) and the World Health Organization Regional Office for Europe (WHO/EURO).

Although the organisers had specific outcomes for the meeting it was essential that the CSO representatives were clear on why the meeting was useful to them and what they wanted to achieve. In addition it was important for them to identify and allocate pre-meeting tasks and who would do/say what during the meeting. As a result of this planning by CSO representatives there was clear reference to CSOs' requests in the final declaration of the meeting. Please see Resources Section 1 for the full example.

A second good example of proactive advocacy is shown in the *Case Study: Proactive advocacy – Catalysing bilateral funding relationships from north–south synergies* (*see pp.16--17*). In this case ACTION partners from Kenya and Japan formed a north–south advocacy strategy to ensure TB was included in the Kenya country proposal for bilateral funding to the Japanese International Cooperation Agency.

Photo courtesy of RESULTS UK.

↘ Photo: **Nick Herbert, UK MP, who had participated in parliamentary delegations to TB programmes in India, Kenya and South Africa speaking about the need for political commitment to TB at the IUATLD meeting in Cape Town.**

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Proactive advocacy – Catalysing bilateral funding relationships from north – south synergies

Problem statement

In 2008, Kenya had one of the highest burdens of TB in the world, with 99,941 patients receiving treatment. Kenya also faced major challenges with TB and HIV co-infection — almost half of new TB cases were among people living with HIV.[3]

In its second National Health Strategic Plan (NHSSP II), the Kenyan government committed to assuring universal access to essential health services. The government also worked to restructure its health delivery system to focus on improved health infrastructure, particularly in rural and severely deprived areas and communities. As part of the NHSSP II, the government developed new goals and a revised strategic plan to address the TB burden within country. To support the plan and to meet the budget requirements for implementation of the strategic plan for TB, the government began to identify new partners and sources of funding.

At the same time, there was limited attention in Japan to the TB situation in Kenya. And, while Kenya had previous bilateral funding agreements with the Japan International Cooperation Agency (JICA), TB was not included as part of past proposals and funding agreements. Realising the opportunity to include TB service provisions in future Kenyan proposals to JICA, ACTION's partners in Kenya and Japan collaborated to capitalise on this funding opportunity.

Objective

ACTION partners, the Kenya AIDS NGOs Consortium (KANCO) and RESULTS Japan, developed a north – south advocacy strategy to ensure TB was included in the Kenya country proposal for bilateral funding to JICA.

Approach

RESULTS Japan pledged to increase the importance of TB amongst Japanese decision makers. As a result of their advocacy, in 2008, five leading Japanese agencies — Ministry of Foreign Affairs; Ministry of Health, Labour, and Welfare; Japan International Cooperation Agency (JICA); Japan Anti-Tuberculosis Association (JATA); and Stop TB Partnership Japan — catalysed Japan's Stop TB Action Plan. With this plan, the public and private sectors pledged to reduce the annual mortality from TB worldwide by ten per cent (160,000 people). Recognizing that foreign aid delivered through JICA is demand-driven, with decisions made by the Japanese Ministry of Foreign Affairs (MOFA), RESULTS Japan and KANCO worked together to create linkages between the MOFA, JICA, and key government offices in Kenya to raise awareness around the opportunity for a partnership through Japan's Stop TB Action Plan.

Key Allies

Japan:
- Japan International Cooperation Agency
- Japan Anti-Tuberculosis Association
- Ministry of Foreign Affairs
- Stop TB Partnership Japan

Kenya:
- Department of Leprosy, Tuberculosis, and Lung Disease
- Japanese Embassy in Kenya
- Japanese International Cooperation Agency in Kenya
- Ministry of Public Health and Sanitation
- Ministry of Finance

Activities

To advance its objective, RESULTS Japan and KANCO worked collaboratively with key allies (mentioned above) to implement a multi-year strategy that included the following key activities:

2007 - Throughout 2007, KANCO held meetings and worked closely with the Department of Leprosy, Tuberculosis, and Lung Disease (DLTLD) to assess the TB funding gap and to identify potential bilateral funders.

2008 - Once the TB funding gap within Kenya was determined, RESULTS Japan conducted an initial assessment on the availability of bilateral funds from JICA, while also gauging the political will for contributions to Kenya. After this initial assessment, the Japanese Foreign Minister to Kenya announced a visit to Kenya. Before the visit occurred, KANCO, along with the Director of the DLTLD, Dr. Chakaya, sent research on the current TB situation within Kenya, along with information on the current TB funding gap. While in Kenya, the Japanese Foreign Minister met with the Kenya Health Advisor for JICA, relevant CSOs, private sector and government allies, and the Kenya Ambassador to Japan, Dennis Awori. KANCO, working with RESULTS Japan, also facilitated meetings between Kenyan civil society and government officials with Japanese Diet members during the Tokyo International Conference on African Development IV, a conference held every five years in Tokyo.

2009 - In follow-up to the 2008 visit by the Japanese Foreign Minister to Kenya, the DLTLD, along with KANCO, drafted a TB-specific proposal for inclusion into the Kenya country proposal for JICA consideration. In addition, RESULTS Japan continued to hold meetings with the Foreign Minister in Japan and other government officials to highlight the TB situation in Kenya as well as the need for additional funding.

2010 - In 2010, due in large part to the partnership between RESULTS Japan and KANCO with key government and civil society allies within Japan and Kenya, the first Kenya JICA proposal that included funding for TB was approved. RESULTS Japan and KANCO continued to work with their respective aid agencies to ensure implementation of the approved proposal would begin in 2011 as agreed.

Outcome

Due to the advocacy efforts of RESULTS Japan and KANCO, a Kenya-wide proposal with the unprecedented inclusion of TB funding was submitted from Kenya's DLTLD to JICA. Through these efforts, KANCO and the DLTLD developed strong working relationships with the JICA office in Kenya. If successfully implemented, Kenya will benefit from the allocation of US $1 – 4 million for laboratory strengthening.

About ACTION

ACTION (Advocacy to Control TB Internationally) is an international partnership of civil society advocates working to mobilise resources to treat and prevent the spread of TB.

ACTION's mission is to build support for increased resources for effective TB control, especially among key policy-makers and other opinion leaders in both high TB burden countries and donor countries. With effective policy advocacy and greater political will, rapid progress can be made against the global TB epidemic.

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End notes

1. From advocacy skills-building workshop for HIV/AIDS, International HIV/AIDS Alliance, Zimbabwe, July 2001.

2. Kenya AIDS NGOs Consortium (KANCO) is a premier national membership network of NGOs, CBOs and faith based organizations involved or with interest in HIV & AIDS activities in Kenya.

3. World Health Organization. 2009. Global Tuberculosis Control: a short update to the 2009 report. Online. Accessed February 10, 2011.
    ↘ **www.who.int/tb/publications/global_report/2009/update/download/en/index.html**

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Section 2

Why advocacy?
The main TB challenges

Photo courtesy of RESULTS UK.

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Why advocacy? The main TB challenges

The contribution of advocacy

As a process to bring about change, advocacy is a key activity for civil society as 'influencer' and 'watchdog', effecting change in programmes and policy and ensuring governments and stakeholders keep to their word.

In global health, and specifically TB, advocacy is a vital part of what we do in the context of resourcing and financing for TB programmes, for research and development. As well as creating a better policy environment for TB programmes to be delivered, advocacy can help to accelerate action to deliver the revised Global Plan to Stop TB and ultimately help to eradicate TB.

↘ **A link to the Plan, which provides updated information on what is needed for TB control worldwide, can be found in Resources Section 2.**

Programme and policy challenges

There are clearly some very major programmatic and policy challenges facing the TB community that call for advocacy work to be scaled up. These cover issues such as multi-drug-resistant TB (MDR-TB), TB–HIV co-infection, reaching populations that are most marginalised and stigma, to name just a few.

Below are some of those key challenges that occupy the time and concern of people working on programme and policy issues.

Multi-drug-resistant TB (MDR-TB)

MDR-TB is formally defined as resistance to isoniazid and rifampicin, the two most effective anti-TB drugs. It has been demonstrated that management of MDR-TB is feasible and effective in resource-limited settings.

In 2008, there were 29,423 MDR-TB cases reported throughout the world by 127 countries.[1] However, these cases only represent about 7% of the MDR-TB cases estimated to have emerged that year. In 2008, an estimated 440,000 cases of MDR-TB emerged globally (3.6% of all new TB patients). Almost 50% of MDR-TB cases worldwide are estimated to occur in China and India. About 100,000 MDR-TB cases are emerging in China annually. To date, 12 countries have reported proportions of MDR-TB of 6% or more among new TB cases. Five of these countries also report MDR-TB proportions of 50% or more among previously treated cases. All of these are located in the eastern part of Europe or in Central Asia. China has reported proportions of MDR-TB of 5.7% among new cases and 25.6% among those previously treated.

↘ **In 2008, MDR-TB caused an estimated 150,000 deaths. For links to further information on MDR-TB please see Resources Section 2.**

! Advocacy point:

Urgent investments in infrastructure, diagnostics and provision of care are essential if the target of diagnosis and treatment of at least 80% of the estimated M/XDR-TB cases is to be reached.

TB–HIV co-infection

TB and HIV are now widely known to be a co-epidemic, one fuelling the rise of the other. This is one of the biggest challenges facing the global TB community today.

Globally in 2007, at least one-third of people living with HIV were infected with TB, and of 9.3 million new TB cases, 1.4 million were also living with HIV. TB is the major cause of death for people with HIV, particularly in sub-Saharan Africa.

↘ For links to an overview of TB–HIV please see Resources Section 2.

❗ Advocacy point:

Greater collaboration and coordination between TB and HIV/AIDs programmes are urgently needed if we are to make headway in the fight against the two diseases.

Adherence to Directly Observed Treatment Short-Course (DOTS)[2]

DOTS remains at the heart of the Stop TB Strategy. The five components of DOTS are:

1 **Political commitment with increased and sustained financing.**
   Legislation, planning, human resources, management, training.

2 **Case detection through quality-assured bacteriology.**
   Strengthening TB laboratories, drug resistance surveillance.

3 **Standardized treatment with supervision and patient support.**
   TB treatment and programme management guidelines, International Standards of TB Care (ISTC), Public-Private mix (PPM), Practical Approach to Lung Health (PAL), community – patient involvement.

4 **An effective drug supply and management system.**
   Availability of TB drugs, TB drug management, Global Drug Facility (GDF), Green Light Committee (GLC).

5 **Monitoring and evaluation system and impact measurement.**
   TB recording and reporting systems, Global TB Control Report, data and country profiles, TB planning and budgeting tool, WHO epidemiology and surveillance online training.

❗ Advocacy point:

So that known constraints can be addressed and new challenges met, further strengthening of the basic five components of the DOTS approach is required.

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Second-line drugs

Second-line drugs are used for treating MDR-TB. However, management of second-line drugs is complex, especially when individualised treatment regimens are used.[3]

Drugs are frequently changed as a result of adverse effects, delayed results and poor response to treatment. In addition, most second-line drugs have a short shelf-life, global production of quality assured drugs is limited, and drug registration may be a lengthy and costly process that is not always attractive to drug manufacturers.

Steps to ensure an uninterrupted drug supply must begin six months or more in advance of the anticipated need, and drug needs must be estimated as accurately as possible.

Countries should only use drugs that have been quality assured by a stringent drug regulatory authority recognised by WHO, a WHO prequalification programme or that meet WHO standards.

! Advocacy point:

Quality assured second-line drugs must be made available to all MDR-TB patients.

Innovative new tools for TB: vaccines, diagnostics, treatment

It has long been recognised that developing new tools for TB – vaccines, diagnostics and treatment – is essential.

Vaccines[4]
The current BCG vaccine prevents serious complications of disseminated TB in children but is not very effective at preventing pulmonary TB, the most common and most infectious form of the disease.

Efficient drug therapy exists, but the treatment is long and case detection rates are low, making the development of a better vaccine an important goal.

What is needed is probably not one, but more likely two or even three new TB vaccine types with different profiles:
- 'priming vaccines', i.e. vaccines intended to replace BCG early in life and before exposure to *Mycobacterium tuberculosis*,
- vaccines to boost anti-mycobacterial immune responses induced by BCG (or its replacement), either early in life (infancy) or later (adolescence/adulthood) when latent TB is/may be installed,
- a therapeutic vaccine against active TB.

It may be that a vaccine can be identified which covers several of these functional profiles, but this will not automatically be the case for all vaccine candidates. It is known that live BCG does not boost anti-TB immunity in latently infected or previously BCG-immunised human individuals or animals.

! Advocacy point:

Investment in research and development of new vaccines is urgently needed.

Diagnostics[5]

Though recent and ongoing advancements in drug therapies offer great promise for saving lives, the unfortunate fact is that new medicines have limited value in the places where TB is rampant. This is because the principal diagnostic tools used in developing countries for determining whether someone has tuberculosis – microscopic examination of stained sputum and chest X-ray – are simply not accurate enough to identify many TB infections.

In addition, many poor and vulnerable people lack access to even these basic diagnostic tools and so do not find out what is wrong with them until it is too late to successfully treat the disease and until long after they are likely to have transmitted the disease to others. The problem is that the cost and sophistication of current new diagnostic tools limit their application to specialised reference laboratories, even in industrialised countries.

What is required are far simpler, accurate point of care tests that can be used in remote health centres to reach the majority of tuberculosis sufferers. Affordability (to the health system) and accessibility (to individuals with suspected TB) as well as high sensitivity are central to determining the impact of any diagnostic test and its ability to accurately diagnose tuberculosis in as many patients as possible.

A new rapid TB test tool has been developed and recently endorsed by WHO.

↘ **See link in Resources Section 2.**

! Advocacy point:

Increasing the speed, effectiveness and accuracy of diagnostic tests is central to the goal of rolling back the global tuberculosis epidemic.

Treatment[6]

Today's TB drug regimen takes too long to be effective and requires too many medications. Treatment of drug-sensitive disease requires 6 – 9 months, and treatment of drug-resistant TB is even lengthier, taking 18 – 24 months or longer. Second-line drugs are also much more toxic and considerably more expensive than the standard first-line anti-TB regimen. Furthermore, current first-line treatment regimens are not compatible with certain common antiretroviral (ARV) therapies used to treat HIV/AIDS. Therefore, new drugs are needed that will be effective in treating children and latent TB infection (an asymptomatic infection), and that will be compatible with ARV therapy. Additionally, new regimens need to be affordable and easily managed in the field.

The introduction of new drugs, preferably with novel mechanisms of action, which will be active against current drug-resistant strains with fewer side-effects, will hopefully allow for a shorter TB regimen for both drug-sensitive and drug-resistant disease. Shortening treatment to four or two months or even less should increase cure rates, improve patient adherence and lessen the likelihood of bacterial strains developing drug resistance.

! Advocacy point:

New improved drugs are needed now to reduce treatment time and improve patient compliance.

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Health human resource capacity

Two key elements remain at the heart of improving the resource capacity for detection, treatment and care of TB.

1 **Human resources (management, planning, quality, quantity, distribution, recruitment and retention)**

2 **Laboratory infrastructure, staffing and capacity.**

Photo courtesy of WHO/TBP/Davenport.

! Advocacy point:

Without adequate numbers of trained healthcare professionals supported to work in the areas of greatest need, TB treatment will fail.

Groups most at risk

There are a number of population groups who are particularly affected by TB. This is mainly because of the environmental conditions in which they live or the condition of their health, already affected by disease. Either of these factors – often linked to poverty – may compromise their immune systems and make them more susceptible to tuberculosis.

People Living with HIV (PLHIV)
HIV infection weakens the body's defences and increases the risk of TB infection progressing to TB disease. PLHIV are also more susceptible to extra-pulmonary TB, such as lymphadenopathy, pleural effusion, pericardial disease, miliary TB and meningitis.

PLHIV (as opposed to AIDS patients) can live well and productively for many years.

↘ **See also links to TB–HIV co-infection in Resources Section 2.**

WHO estimates from 2009[7] show that 11–13% of incident cases were HIV-positive; the African Region accounted for approximately 80% of these cases. There were 0.38 million deaths among HIV-positive people (range 0.32 million–0.45 million) and most cases were in the South-East Asia, African and Western Pacific regions (35%, 30% and 20%, respectively).

! Advocacy point:

Diagnosis and treatment of TB in people infected with HIV is essential to reduce unnecessary deaths of people with HIV/AIDS.

Drug users

The term 'drug users' is preferable to drug addicts or drug abusers. The latter are seen as derogatory terms and often result in alienation rather than creating the trust and respect needed in dealing with people who inject drugs. Drug users have high rates of HIV infection with the greatest risk for HIV infection being injecting behaviour. Drug users also have increased rates of TB infection, whether living with HIV or not, though HIV increases the risk of developing TB disease. There is an overlap between countries where the HIV epidemic is mainly driven by injecting drug use, and those with some of the highest rates of MDR-TB.

Drug users tend to be a marginalized group with complex needs and poor access to life saving interventions. Health systems have often responded with separate policies and structures, to the detriment of the individual user and their communities.

Homeless people and slum-dwellers

These can be marginalised groups with limited access to information and healthcare services. They live in conditions prone to TB infection (e.g. overcrowded, with poor ventilation) and often with malnutrition.

For example, in Ivanovo Oblast[8] (Russia) the TB case fatality rate (during treatment) was higher among homeless patients than among other patients. Again, because of the conditions in which they live, this group is particularly vulnerable to TB.

Populations in closed settings (e.g. prisons)

Large populations living in restricted circumstances where there is overcrowding and poor conditions are susceptible to TB. In the former Soviet Union, TB in prisons is a huge public health problem. In Russia, for example, the prevalence of TB disease was estimated in 2005 to be about ten times greater among prisoners than in the general population.

Migrating populations (e.g. refugees and miners)

Many infectious diseases, such as HIV/AIDS and MDR-TB, can cross borders via population movements. Migrants are a vulnerable group and are likely to have unmet health needs including particular mental health needs. They may face language and cultural barriers and discrimination. In the countries they migrate to, they may be locked into menial jobs. Taking care of the health needs of migrant populations is also in the best self-interest of host countries.

! Advocacy point:

Quality assured second-line drugs must be made available to all MDR-TB patients.

Photo courtesy of RESULTS UK.

! Advocacy point:

Poor living conditions have a major impact on the spread of TB and must be addressed alongside treatment.

! Advocacy point:

Better accommodation as well as improved care for prisoners will reduce the spread of TB in prisons.

! Advocacy point:

Identifying and treating TB amongst migrant populations will serve both the patients and the host countries.

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Previously treated TB patients (vis-à-vis MDR-TB)

Prior exposure to anti-TB drugs is a well-established risk factor for TB drug resistance, as shown from numerous surveys and surveillance systems worldwide.

For instance, a nationwide drug resistance survey in China, conducted in 2007, revealed a proportion of MDR-TB of 25.6% in previously treated cases.[9]

> **Advocacy point:**
>
> **Better and more appropriate first-line treatment of TB will avoid the risk of MDR-TB.**

Photo courtesy of WHO/TBP/Davenport.

↘ Photo: **Newly diagnosed TB patient outside her house in Dhaka, Bangladesh.**

Stigma

One of the greatest obstacles that people with TB must face is the stigma associated with the disease. At a time when support is most needed, TB patients often find themselves most shunned. On the whole, stigma is born out of fear and misinformation. In some communities, it is assumed that TB is the result of poor hygiene, a lack of education, and destitution. In reality, although factors such as poor hygiene and destitution can increase the likelihood of transmission and progression of TB, these factors do not cause TB. In some countries TB is thought to be the result of previous wrong doings, witchcraft or poisoning.

Because of stigmatisation, many people with TB are afraid that neighbours and community members will find out they are infected and so retreat into a world of silence and isolation. This can lead many people with TB to delay seeking treatment, which can in turn lead to higher rates of transmission.

> **Advocacy point:**
>
> **Stigma must first be acknowledged and then addressed at all levels of society.**

↘ **A tool to address the dual stigma of TB and HIV has been developed by the AIDS Alliance together with ZAMBART. See link in Resources Section 2.**

Human rights violations in the context of MDR-TB

In some circumstances, personal dignity and patients' rights have been compromised in the process of delivering TB care as part of TB control efforts. Fundamental ethical norms for public health and clinical practice may not always have been applied.

Some of the steps taken by governments, service facilities and providers in the interests of public safety include measures that do not effectively balance the protection of the rights and health of the general public with those of the people suspected of or confirmed as having TB.

Public concern about MDR- and extensively drug-resistant TB (XDR-TB), poor information and consequential stigma, severely constrained manpower and resources, all may further complicate and compromise careful decision-making. In some instances this has led to a severe restriction of rights, for example the broad rather than exceptional use of involuntary detention or isolation of TB patients.

Ethically compromised practices may also be closely linked to inequitable access to, and poor quality of, prevention, care and health promotion related to TB and other health challenges.

Poor, vulnerable and highly marginalised groups are most likely to become infected with TB and to suffer poor outcomes when illness occurs and are the most in need of advocacy to put their case.

! Advocacy point:

The rights of the individual patient must be a key priority in all treatment regimens.

Some urgent issues

Currently, many National TB Programmes (NTPs) may have incomplete answers and policies to questions relevant to the ethical design and conduct of services, particularly in light of MDR-TB. The capacity to answer these questions within a sound ethical framework may be weak or even non-existent in some countries.[10]

Advocates should be finding out, for example:

- What is best practice for care of patients and infection control if MDR- or XDR-TB is suspected and diagnostic tests and second-line medicines are not yet readily available?
- If adequate TB infection control practices are not yet in place in major hospitals where should infectious TB patients be treated initially?
- What are the limits of healthcare workers' 'duty to treat', especially in the absence of proper infection control measures?
- What human rights principles and local laws are being applied in the decision-making regarding the use of involuntary detention?
- Are the International Standards of TB Care, the Patients Charter for Tuberculosis Care, International Health Regulations and ethical standards in TB research and surveillance being applied?

End notes

1.   Multidrug and extensively drug-resistant TB (M/XDR-TB): 2010 global report on surveillance and response.
      ↘ **http://whqlibdoc.who.int/publications/2010/9789241599191_eng.pdf**

2.   Pursue high-quality DOTS expansion and enhancement, WHO.
      ↘ **www.who.int/tb/dots/en**

3.   From Guidelines for the programmatic management of drug-resistant tuberculosis Emergency update 2008, WHO.
      ↘ **www.who.int/tb/publications/2006/who_htm_tb_2008_402.pdf**

4.   From Stop TB Working Group on Vaccines.
      ↘ **www.stoptb.org/wg/new_vaccines**

5.   From: Pathways to better diagnostics for tuberculosis. A blueprint for the development of TB diagnostics. The New Diagnostics Working Group of the Stop TB Partnership.
      ↘ **www.stoptb.org/wg/new_diagnostics/assets/documents/BluePrintTB_annex_web.pdf**

6.   From Stop TB Partnership Working Group on New TB Drugs.
      ↘ **www.newtbdrugs.org/about-overview.php**

7.   WHO Report 2010. Global Tuberculosis Control.
      ↘ **http://whqlibdoc.who.int/publications/2010/9789241564069_eng.pdf**

8.   WHO, Addressing Poverty in TB Control – Options for National TB Control Programmes, 2005, p. 17.

9.   WHO, Multidrug and Extensively Drug-Resistant TB: 2010 Global Report on Surveillance and Response, pp. 10–11.

10.   Providing M/XDR-TB management and care, A Ministerial Meeting of high M/XDR-TB Burden Countries, Beijing, China, April 2009, p. 21.

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Section 3

How to plan for successful advocacy

Photo courtesy of RESULTS UK

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How to plan for successful advocacy

Many opportunities for advocacy do exist. However, if we are to bring about real change in TB practice and care and truly make a difference, then advocacy needs to become a part of our everyday lives, addressed daily and persistently.

Some countries and regions already have systems in place that are more conducive to advocacy. But whether opportunities for advocacy exist in your country or not, for it to happen, a crucial first step must be to get clear on what change you want to see happen and develop an advocacy strategy. This section covers overall planning. **Section 4** covers who we are trying to influence – our targets and **Section 5** some of the skills we need for successful advocacy.

Develop an advocacy strategy

Developing an advocacy strategy is frequently done by instinct, a certain amount of guess work and even hope.

However, this approach can be erratic and unsuccessful in outcome. The best approach is to get together with the people you will be working with and develop a strategy you can align behind and which will also provide a useful baseline against which to measure progress.

On the right are the key steps to developing an advocacy strategy.

"The best approach is to get together with the people you will be working with and develop a strategy you can align behind and which will also provide a useful baseline against which to measure progress."

i Advocacy strategy[1] Key steps

Step 1. Select an issue or problem/policy change you wish to address.

Step 2. Analyse and research the problem and solutions to it.

Step 3. Develop specific objectives for your advocacy work.

Step 4. Identify your targets (who will you influence?).

Step 5. Identify your resources (what funds will you need? What other resources do you have?).

Step 6. Identify your allies (who will you work with?).

Step 7. Create an advocacy plan with specific goals, outcomes, dates and responsibilities.

Step 8. Implement, monitor and evaluate your work (ongoing, and amend it as you go along).

Create an advocacy plan

Within an advocacy strategy, we need to create an advocacy plan (see Step 7). The first step is to define/identify expected outcomes – what kind of specific change needs to be brought about and when?

The key elements of an advocacy plan are also critical components of a project funding proposal and if identified will help in the development of such proposals.

Key elements to a successful advocacy plan

There are **4** key elements to a successful advocacy plan:

1 **Overarching goals** – to give us focus. How else will we know where we are going and if we have succeeded?

2 **Measurable outputs** – so we know what we have achieved along the way to reaching our overarching goals.

3 **Timeline** – including end point and key steps along the way.

4 **Activities** – covering all areas and linked to outputs.

- What is your objective?
- Who will you target?
- What key activities will be undertaken?
- Who will do the work and who will you work with?
- How will you go about your activities, e.g. meetings, press work, etc.?
- What is your timeframe – for each activity?
- What key dates, e.g. deadlines for signing agreements, meetings etc. do you need to keep in mind?
- Who will have overall responsibility for ensuring the plan is delivered?

An example of a good advocacy plan is one developed by the UK Coalition to Stop TB[2] that formed working groups and established advocacy plans for each group.

↘ **The TB/HIV working group plan for 2010 can be found in Resources Section 3.**

Set goals and objectives

One of the most difficult things to do when developing your advocacy plan is to identify your overarching goals and specific objectives.

First it is useful to distinguish between goals and objectives.

A goal

A GOAL is not usually too specific.

A GOAL is often a broad statement that gives us an opportunity to clarify our vision and provide a focus for our work over the long term.

A GOAL will frequently be immeasurable – it won't necessarily have specific numbers or a timeframe in it.

A GOAL is usually looking long term (will not be realised in the short term).

Example of a goal:
All South Africans will have universal access to TB prevention and treatment services.

An objective

Objectives are realistic targets for our work. They will provide the steps we need to take in order to achieve our goal.

AN OBJECTIVE is usually written in an active manner.

AN OBJECTIVE helps focus our activities.

AN OBJECTIVE will answer some key questions – Who is going to do what, when will they do it, by when, why and to what standard?

Example of an objective:
By the end of this year all appropriate Russian media will have received awareness training on MDR-TB.

Creating **SMART** objectives - Being SMART with our objectives is key:

Specific

Specific: Why are we doing this and for whom and what? To improve knowledge, increase awareness, build capacity etc.

Measurable

Measurable: Is it measurable and can we measure it? Measurement depicts movement and change – something is more or better than it was before, e.g., it has increased, enhanced, built capacity, etc.

Achievable

Achievable: Can we get it done in the proposed timeframe/in this political climate?

Relevant

Relevant: Will it lead to desired results?

Time-framed

Time-framed: When will it be accomplished?

Types of objectives (Adapted from Treatment Action Group (TAG), New York.[3])

There are three main types of objectives:

① Process:

Being accountable by setting numbers/types of activities—what you are doing and how you'll do it.

Example:
By December 2009, I will educate 30 decision-makers in influential positions on TB/HIV co-infection.

② Impact:

How you will change attitudes, knowledge and behaviour in the short term.

Example:
At the end of this year, the 30 decision-makers who were educated can explain how TB impacts HIV disease.

③ Outcome:

Long-term implications of your work (rarely measurable as the result of a single project).

Example:
By 2015, rates of TB/ HIV co-infection will have decreased by 25% in my country.

Suggested activity

Develop one goal and one of each of the objectives for the following four programme or policy concerns/challenges:

1. Intensified case finding of TB disease among people with HIV.
2. Improved detection and treatment of MDR-TB.
3. Infection control in HIV care settings.
4. Ring-fenced/ear-marked funds for TB care and control.

Examples:

Goal: Overall case finding of TB among all people with HIV in Africa will be increased.

Objective (Process): By January 2011 all HIV health workers will be educated on the need for TB testing.

Objective (Impact): By the end of 2011 all HIV health workers will fully understand the reasons why TB testing is important and be putting this into practice.

Objective (Outcome): By the end of the decade no TB case among HIV patients will go undetected.

! Some **hot** tips

- Do not write objectives like activities and visions
- Do not write too many.

Photo courtesy of Advocacy Partnership

↘ Photo: **Training participant helps lead session on setting goals at TB advocacy training in Cape Town, South Africa.**

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End notes

1. Adapted from an advocacy framework developed by the International HIV/AIDS Alliance. Advocacy in Action: A tool kit to support NGOs and CBOs responding to HIV/AIDS, 2003.

2. The UK Coalition to Stop TB is a network of over 30 organisations working to stop TB. It was formed in 2008 to increase awareness, commitment and the political will to address TB through coordinated actions and a unified voice.

3. Types of objectives, adapted from Always be SMART: setting goals and objectives, TAG, New York. Personal Commmunication.

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Section **4**

Photo courtesy of RESULTS UK.

Who are we trying to influence?

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Who are we trying to influence?

Understanding the decision-making process

Advocacy has a key role to play in setting the agenda of any decision-maker, including government, and in monitoring all decision-makers' commitments. By acting as effective agents for change, advocates can ensure that appropriate policies, laws, programmes and resources are in place to effect real change in TB control and care.

Furthermore, advocates can, through their actions, make sure that progress is sustained and that decision-makers are held accountable over time.

What advocates need to know

Advocates will need to have a basic understanding of how decisions on TB are made in their country or region and of the political climate in which they take place. They will also require knowledge of competing priorities if they are to influence change.

It will be necessary to find out what the views and actions of decision-makers are on such issues as public health, TB services and the size and challenges of the TB problem in their country. In most cases, leaders' views are a matter of public record and are probably well known to CSOs and advocates.

As a prerequisite for sound policy alternatives, advocates will need to know how to analyse existing TB policies and/or laws as well as identify their shortcomings.

> What commitments, for example, did your country make at the G8 Summit in 2010 or the Global Leaders Forum on TB–HIV at the UN in New York in 2008?

> Is your country honouring those commitments?

By analysing the policy environment for TB, advocates can identify specific policy issues. For example, in Russia X-rays are used in the detection of all TB cases and it may be more effective to push the DOTS strategy.

Understanding the background to a particular policy will help determine how difficult it is likely to be to change that policy. It should also help the advocate anticipate which groups will oppose reform and which groups will support it. For example, has pressure already been exerted by special interest groups concerned mainly with protecting their own interests?

Opening a dialogue with those we wish to influence

Most countries have some space for dialogue with decision-makers. Even in those countries with fledgling structures, there are forums where influence can happen. A good example is the Country Coordinating Mechanism (CCM), created by the Global Fund to Fight AIDS, Tuberculosis and Malaria (GFATM). For those CSOs that are not members of a CCM it should be noted that the following is one of the six minimum CCM requirements:

> "CCMs are required to create a transparent, documented process which ensures that CCM members and non-CCM members have the opportunity to contribute to proposal development and in conducting grant oversight."

↘ **Links to further information on minimum requirements for CCMs can be found in Resources Section 4.**

In the context of the CCM, CSOs are required to:

- Identify strategy priorities and a common advocacy agenda.
- Improve a range of technical skills and capacities: medical information and disease-fighting strategies; structure, function and procedures of the CCM and Global Fund; members' roles and mission on the CCM; high-level advocacy and negotiation skills; skills for communicating with constituencies; programme management and logistics; monitoring and evaluation; and government budgeting, financing and legislative processes.
- Improve communication across civil society.
- Mitigate conflict of interests (for instance, when a CSO member of the CCM is a recipient of the Global Fund) and be accountable to the wider civil society and affected communities.[2]

Country Coordinating Mechanisms (CCMs): dialogue space

CCMs are central to the Global Fund's processes at country level to ensure local ownership and participatory decision-making. CCMs are responsible for developing and submitting grant proposals to the Global Fund Secretariat. Once a grant is approved, CCMs oversee progress during implementation.

CCMs bring together representatives from both the public and private sectors, including governments, multilateral or bilateral agencies, NGOs, academic institutions, private businesses and people living with the disease.

There are issues around CCM governance,[1] e.g. members ineffective at representing their constituencies; obstacles to CSOs actively participating and leading in CCM processes; poor representation of marginalised groups/affected communities etc. However, CCMs are recognised as a potential space where CSOs can engage with governments and an enabling environment for advocacy work can be fostered.

This is true also in countries where previously there had not been space for dialogue between civil society and government.

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Who we want to influence to achieve policy change

Who we identify as the decision-makers we want to influence will depend not only on our overarching goals and objectives but on the country in which we work and the specific challenges we face.

Regardless of a country's political system or receptiveness to popular participation, efforts by advocates and CSOs in the government arena will target a range of stakeholders to effect policy change.

These include the executive, legislature/parliament, judiciary, government ministries and agencies (not just those covering health but also education, prisons etc. local officials and health professionals.

Political decision-makers at local, regional and national level

Wherever we live, political decision-makers working at the local or national level are key to influencing policy.

We need to identify who they are, and educate and influence them about our issues.

How to influence political decision-makers
One of the most effective ways to influence policy is to create champions amongst the elected representatives in the parliaments and other governing bodies in the country in which you work.

However, a champion is not someone who merely votes the right way or supports a bill/policy your organisation supports. A champion is a member of Parliament or Congress or Duma (or whatever the elected body in your country is called) who takes on the issue as a priority and does their utmost to make sure change happens.

Who else influences political decision-makers?
We need to have a basic understanding of how political decision-makers do their jobs. Most are informed by the following sources: colleagues, staff members, constituents, media, experts, and by their own experiences.

When they consider taking an action, they will ask themselves:

- Am I out here on my own or will I have support from my colleagues?
- What information does my staff have on this issue?
- What will my constituents think?
- Will I get attacked or face serious opposition in the media?
- And will this action make a difference? Is it worth fighting for?

It's vital to keep these considerations in mind to make you a more effective advocate. Reaching out to other influencers, e.g. staff, colleagues and the media, and building relationships with them, will be crucial to the success of your advocacy campaign.

Key steps in working with political decision-makers

Identification:
Which politicians do you need to influence? What do they know already? What else do they need to know?

Engagement:
Reaching out and building a relationship/partnership.

Education:
What do they need to know, see and hear? How can I best do this? Who can I introduce them to?

Motivation:
What will motivate them into action? Why would they care? What can I show them that will make a real difference?

Action:
What specific actions do I want them to take? Who else can they work with on it?

Influencing role of colleagues

Political decision-makers are influenced by their colleagues. So it's important that you ask them to speak to the leaders of key committees responsible for TB or even broad health issues.

Here's a short story from RESULTS US[3] to illustrate the power of this approach.

For many years Representative Sonny Callahan chaired the committee in the House of Representatives responsible for the foreign aid budget. In one of his last speeches as Chairman, he said that more of his colleagues had expressed support for international child health programmes than for any other programme in the foreign affairs budget and that he considered it the most important issue that he had ever worked on in Congress.

It was RESULTS volunteers around the country who had urged their members of Congress to speak to Representative Callahan in the first place **– an advocacy success!**

Influencing role of the media

Political decision-makers are also influenced by the media — both local and national – so it's important to know how to generate media, especially print media.

↘ **Hints on writing letters to the editor and opinion pieces, and how to have effective meetings with local editorial writers and journalists follow in Section 5.**

Photo courtesy of RESULTS UK.

↘ Photo: **Tom Clarke, UK MP, meets local children on parliamentary delegation to TB clinic in India.**

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How to work with and influence decision-makers

Tactics to influence decision-makers are varied and can be either 'direct' or 'indirect'. Direct advocacy uses methods to personally engage and educate decision-makers, whereas indirect advocacy uses methods that try to change social agendas and mobilise large groups of people.

At RESULTS UK, for example, direct advocacy is used, and a distinction is made between 'policy' advocacy, e.g. individual meetings, briefings, personal letters appealing to policy-makers and their staff, and 'bureaucratic' advocacy, e.g. strategically utilising public sector officials from WHO, the Stop TB Partnership and the Global Fund to educate key policy-makers.

RESULTS has also used coalition advocacy for TB to build upon small existing coalitions or tapped into other pre-existing networks. If a pre-existing network is not yet established you may need to actually build a committed and strategically focused constituency, even a small one.

> Tactics to influence decision-makers are varied and can be differentiated as either 'direct' or 'indirect'.

'Inside'/'outside' advocacy

One of RESULTS' most successful advocacy approaches capitalised on synergies between bureaucratic advocacy and policy-maker advocacy, combining what became known as the 'inside'/'outside' approach.

This maximises the use of conventional institutional channels to increase resources and heighten awareness.

Recognising that 'inside' strategies alone are not sufficient in creating political will, pressure from other parties is required to hold governments accountable for achieving results.

For this approach to succeed, it is essential that advocates have an appreciation of the institutional constraints of the bureaucratic partners with whom they are working. Conversely, it is necessary for the bureaucratic partners to be proactive in providing their advocacy partners with useful support and timely information.

TB has yet to really benefit from mass advocacy strategies and there could be some value in mixing this with policy-maker/bureaucratic advocacy.

↘ **The ACTION project[4] has helpfully defined the various types of advocacy by their immediate audiences and this can be found in Resources Section 4.**

Building personal relationships

Building a successful personal relationship with a decision-maker needs to be based on the premise that you and the decision-makers are ultimately working towards the same goals – a better world, improved health etc.

The ways in which you achieve those goals may differ, you may have different tactics, partners, agendas, including personal ones. But the bottom line is that if you want to influence people who have the power to make decisions then you need to be speaking to them. You need to be working with them. And to do that you need to be building relationships with them.

Within that context there are things you can easily do (have meetings, write letters, form coalitions, get published in the media, challenge (*using 'inside'/'outside' advocacy – See Box*).

If you are not able to build a 'relationship' with the people you want to influence, you will probably fail.

Key components in building relationships

- **Find out who the person is** – everything you can from every source – their interests, what they are committed to, their history, what action they have taken in the past.

- **Relate to them as human beings** – not as an institution.

- **Find common ground** – there is always something!

- **Acknowledge them** – maybe for meeting you, some action they have taken.

- **Ask what they need to help move the cause forward** – see if you can provide that.

- **Offer to help** – provide information or resources.

- **Be polite and clear with your messages** – they will want to listen if you have covered all the above points.

- **Inspire them with your passion** – (not anger).

- **Follow-up on action agreed** – (including your own).

- **Keep your promises** – as a model for them.

- **Generate genuine partnership** – it's easier and will serve both partners.

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Building coalitions/networks/partnerships

If you are building a coalition or a network of partners you need to make sure you don't just include NGOs and scientific organisations but engage those groups or individuals who are living with TB. It is vital to bring their perspective and find ways for them to meaningfully engage (*see Section 5, Skill 1: Creating parliamentary champions*).

According to advocacy experts there are three key elements that form the building blocks of advocacy:

1. The formation of coalitions (groups or networks)
2. The identification of political opportunities
3. The organisation of campaigns.

We address the first key element here. Building a coalition is quite simply designing a process or a forum that will enable contact with other individuals and organisations that share or support common goals and agree to work together to achieve those goals.

A coalition can use advocacy to engage in high-level dialogue with policy-makers and other influential leaders on broad policy issues and national policies with sometimes greater impact than organisations operating alone.

To be successful in advocacy, coalitions need to be well organised and operate efficiently. Their founding members must have the time and energy to initiate the group and be able to resource or find the resources to fund the coalition's activities. They need to be able to harness the talents of others and skilfully take advantage of opportunities to influence the policy process.

To be effective advocates, all coalition members must develop skills that enable them to engage in dialogue with decision-makers at all levels.

UK Coalition to Stop TB

The UK Coalition to Stop TB was formed in 2008 after many years of organisations working separately and sometime jointly in advocacy activities. The formation of the Coalition gave a much needed focus to these advocacy activities and gave the TB community in the UK a platform from which to work in partnership with those they wanted to influence. It was formed to increase the level of awareness, commitment and political will to address TB through coordinated actions and a unified voice. The Coalition is a national partner of the global Stop TB Partnership.

Membership of the UK Coalition to Stop TB is open to organisations and individuals working to address the TB epidemic in the UK and internationally, including, for example, NGOs, the private sector, media, advocates, academic institutions and professional organisations. Members of the UK Coalition to Stop TB meet quarterly to coordinate actions and agree future priorities.

Working groups meet on a more regular basis to focus on specific issues and outcomes. The Coalition's current areas of focus and working groups are:

- HIV/TB and drug-resistance
- TB in the UK
- Resource mobilisation
- Research and new tools
- Media

Working with the media

Working with the media and engaging them in your advocacy work is going to dramatically impact the outcome of your campaign. Easier in some countries and regions than others, it is still worthwhile bringing media contacts on board.

Your local paper, radio station or newscasts can be powerful tools for getting others in your community invested in TB issues.

Some actions you can take to engage the media:

- Write a letter to the editor and send your published letter to your political decision-makers.
- Write or generate an op-ed and send your published piece to your political decision-makers.
- Meet face-to-face with a journalist or the editorial board of your local paper.
- Generate an editorial or article in your local paper and send a copy to your political decision-maker.
- Organise a press conference.
- Create an opportunity for you and others, including your political decision-makers, to regularly contribute to public dialogue via a weekly column or blog.

↘ **For more information on working with the media see links to organisations listed in Resources Organisations, in particular RESULTS US and Panos.**

↘ **Specific skills on working with the media can be found in Section 5.**

Working with government officials

Often the people who most frequently advise political decision-makers are government officials, or advisors, especially those with a remit for TB. They are people to reach out to, meet with and begin to develop a good working in relationship with – to bring them on board as partners in your TB advocacy campaign.

The UK All Party Parliamentary Group on Global TB[5] has membership from a wide TB stakeholder sector, including government officials, and their meetings enable greater dialogue to take place.

Photo courtesy of RESULTS UK.

↘ Photo: **UK parliamentary delegation members discuss TB with decision-makers of National TB Control Programme in India.**

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Key messages for TB and MDR-TB advocacy

It is vitally important in the influencing work you do to think about and develop messaging that is meaningful and appropriate for your audience.

Once you have identified your audience and have their attention you will only really have influence if you use language and tell stories that they understand and remember.

↘ **We will look at this in more detail in Section 5, Skill 4: Speaking powerfully.**

In the meantime, it is important to remember that a powerful advocacy campaign must have key messages that are clear and speak to the people we wish to influence.

Remember to use messages that:

- Are significant – they get to the 'root' of the problem
- Are easy to remember
- Mobilise action.

A good example is the messaging in the UK Coalition election manifesto document.

↘ **See Box UK Coalition to Stop TB: 'TB Election Asks' 2010.**
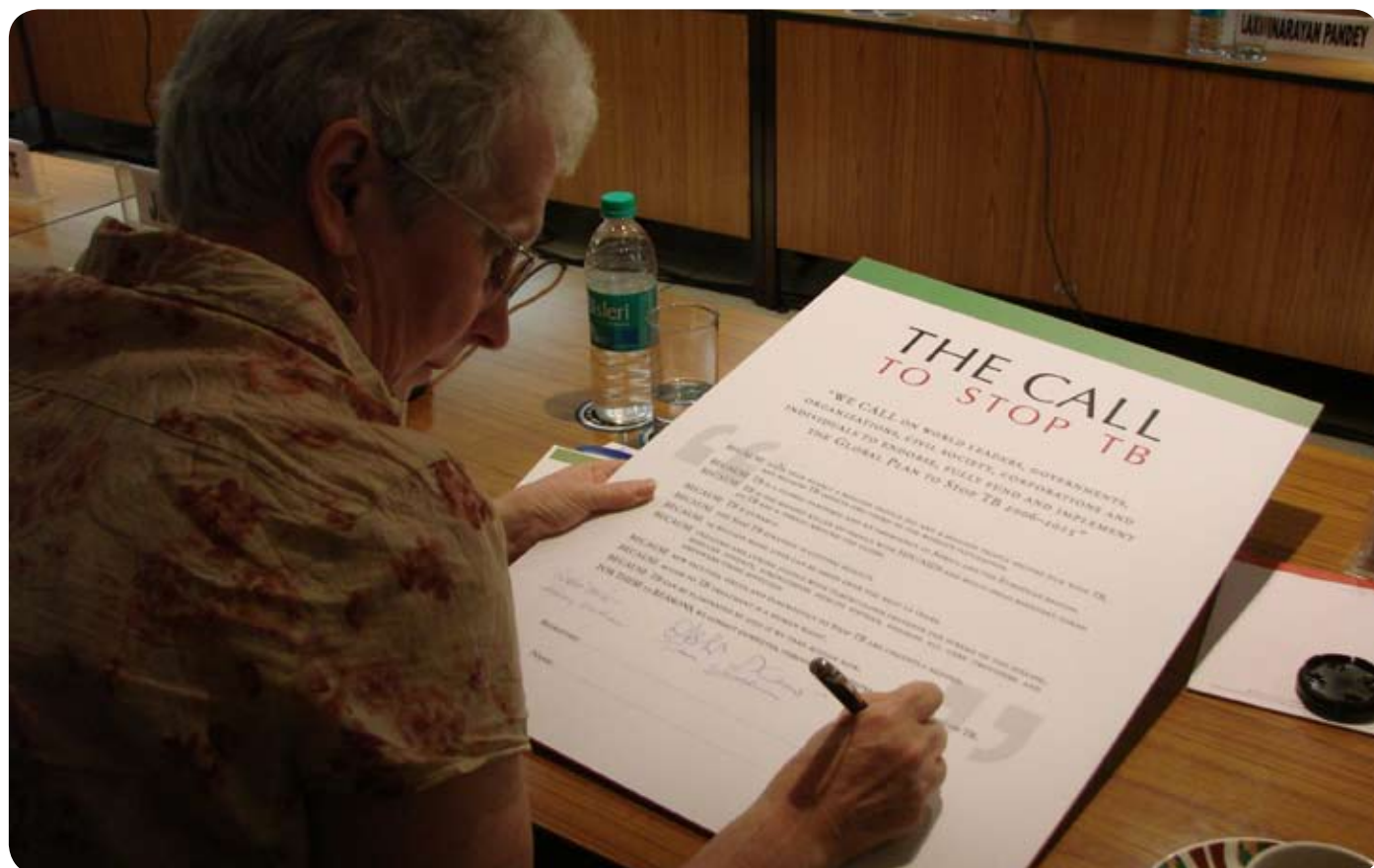
↘ Photo: **Anne Cryer, UK MP, on a Parliamentary delegation to India to see TB programmes signing the Call to Stop TB during a joint meeting with Indian Parliamentarians.**

UK Coalition to Stop TB: 'TB Election Asks' 2010

On the eve of a UK general election, the UK Coalition to Stop TB urged a new UK Government to ensure that TB is made a priority within its domestic and global heath agenda. They called on all parties to review their plans in light of these asks.

This called on a new Government to:

TB in the UK:

- Prioritise TB within the broader UK health agenda and review and update the Chief Medical Officer's TB Action Plan 2004 with time bound, monitorable objectives.

- Develop a clear set of monitorable National Standards for the provision of TB care in the UK. This should include a UK Patient Charter to ensure equity in access to TB care and clearly highlight where accountability lies for failings in TB service provision.

TB globally:

- Increase the UK's financial contribution to fighting TB globally to ensure the Global Plan is fully funded and the Global Fund to Fight AIDS, TB and Malaria Replenishment Conference in October 2010 is successful with the UK contributing its 'fair share'.

- Mainstream TB into all of the Department of International Development (DFID)'s health programmes including HIV/AIDS, nutrition and maternal health and ensure programmes are properly focused to have an impact on reducing TB mortality and incidence.

- Review progress towards and update the DFID's 2005 Practice Paper on TB and Malaria.

- Ensure TB is prioritised at the MDG Review Summit in September 2010; that progress towards the MDG on TB is reviewed, and a plan developed to ensure that the target is met in all regions by 2015. Prioritise TB at other international forums such as the G20, the European Union and the World Health Assembly.

- Acknowledge TB as a disease of poverty and continue to address the social and economic determinants that make people vulnerable to TB. Specific actions will be needed for hard to reach, marginalised and most vulnerable populations. This should include promoting intensified case finding in both the UK and globally.

- Acknowledge the role of strong TB programmes in health systems strengthening, including providing reliable access to diagnosis, treatment and vaccines, whilst ensuring that Sector-Wide Approaches (SWAPS) do not undermine specific disease programmes such as TB.

- Prioritise integration of TB and HIV programmes and joint testing for TB and HIV and ensure universal access to HIV prevention, treatment, care and support includes TB prevention, diagnosis and treatment.

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End notes

1. Brugha, R. et al, "The Global Fund: Managing Great Expectations",The Lancet, Volume 364, Issue 9428, pages 95–100, 3 July 2004. The International HIV/AIDS Alliance, Report on access to Global Fund resources by HIV/AIDS Key Populations in Latin America and the Caribbean, April 2009.

2. International Treatment Preparedness Coalition (Treatment Monitoring and Advocacy Project), CCM Advocacy Report, Making Global Fund CCMs work through full engagement of civil society, October 2008, pp. 3–7.

3. RESULTS and RESULTS Educational Fund are sister organisations which, together, are a leading force in ending poverty in the United States and around the world.
    ↘ **www.results.org**

4. The Advocacy to Control Tuberculosis Internationally (ACTION) project is an international partnership of advocates working to mobilise resources to treat and prevent the spread of tuberculosis (TB).
    ↘ **www.action.org**

5. The All-Party Parliamentary Group on Global Tuberculosis was established in 2006 in response to cross-party concern for the growing scale and impact of the TB epidemic and to reinforce the UK's commitment to halting and reversing the incidence of TB worldwide.
    ↘ **www.appg-tb.org.uk**

Advocacy skills

In this section, we look in detail at some of the skills that you will need to become a successful advocate. These include skills you need when working with decision-makers and the media, such as cultivating parliamentary champions, active listening, developing messages and writing for the media.

The skills covered are based on successful advocacy we know or have experienced and suggest an activity for you to try.

Skill 1: Creating parliamentary champions

Skill 2: Developing messages

Skill 3: Preparing informative briefing material

Skill 4: Speaking powerfully

Skill 5: The one-minute message

Skill 6: Effective meetings

Skill 7: Active listening

Skill 8: Working with the media

Skill 9: Preparing a press release

Skill 10: Writing for the media

Photo courtesy of RESULTS UK.

advocacypartnership

Advocacy skills

Skill 1: Creating parliamentary champions

This section is drawn from experience with RESULTS UK[1] which over a ten-year period identified and built relationships with parliamentary representatives so that they could act as 'TB champions' amongst their colleagues in Westminster.

The focus of all of RESULTS' work is on generating political will because it acknowledges that politicians are the gatekeepers to higher powers and those who hold the purse strings and have leadership.
Developing parliamentary champions for TB was thus critical if the organisation was to meet its objective of increasing UK Government TB funding.

The work focused on educating MPs on TB, the scale of the problem, what needed to be done and what the UK could do – as well as on taking MPs to see TB programmes in high-burden countries (HBCs) for themselves. MPs could in turn:

- Influence key decision-makers in Government and the Department for International Development (DFID) on budget priorities;
- Take up issues with multilateral institutions e.g. World Bank, the International Monetary Fund (IMF) and the Global Fund,
- Give TB a higher political profile within parliamentary groups, the media and amongst government leaders;
- Influence TB to be a policy priority in HBCs.

The first step in the process of creating parliamentary champions – building relationships with political decision-makers – has been covered in Section 4.

What is covered in this section is how to work with political and patient advocates to build 'champions' for the TB cause in order to bring an end to TB.

Over the years, RESULTS UK has engaged over 60 members of the UK Parliament through one-on-one and group briefings to educate them on TB and TB–HIV issues.

This is something you could do!

Those that RESULTS has met and educated on TB include:
- Secretary of State for International Development.
- Shadow Secretaries of State for International Development (of both main opposition parties).
- Chairs of the All-Party Parliamentary Groups on AIDS and Poverty.

Through these educational briefings MPs have in turn generated questions in the House of Commons and meetings with decision-makers such as the Prime Minister and Chancellor of the Exchequer.

i First steps to building political champions

- Education and empowerment – known as 'enabling'.
- Exposure: either by taking them to the story through delegations to HBCs or bringing the TB story to them, through advocacy tours to the UK by TB experts.

Some key strategies for engaging MPs

- Meeting and briefing MPs.
- Hosting TB activists and experts in the UK to inform and inspire MPs.
- Generating politically significant media on TB at national and regional level.
- Reinforcing efforts through a grassroots citizens' network, e.g. meeting with their MPs.
- Providing MPs with first-hand experience of TB programmes in high-burden countries, e.g. the parliamentary delegation to Kenya.

Advocacy tours: working with TB experts and patient advocates on UK activities

RESULTS has on several occasions hosted 'experts' on TB in the UK.

For example, Zambian TB activist Winstone Zulu and Kenyan nutritionist and TB–HIV activist Lucy Chesire, both patient advocates, and Felix Salaniponi, TB Controller in Malawi, have visited the UK and briefed MPs and parliamentarians numerous times.

They are among the many 'experts' who have played a key role in educating MPs in the UK, as well as generating media on the issue of TB and TB–HIV.

Their activities that helped TB be seen as a priority include:
- A briefing at the House of Commons by Winstone Zulu
- A meeting at DFID on TB–HIV with Lucy Chesire
- A personal letter to Prime Minister Tony Blair delivered to Number Ten Downing Street by Lucy Chesire
- A meeting between Felix Salaniponi and Shadow Secretary to State for International Development Andrew George, who later went on to be part of the UK Parliamentary delegation to Kenya and later chaired the APPG on Global TB.

These meetings were supported by staff (Paul Nunn, Dermot Mayer and Glenn Thomas) of WHO/the Stop TB Department, who helped with the technical side of TB programmes and WHO policy on TB.

Generating media events with parliamentary champions

RESULTS has found it invaluable to work with partner Glenn Thomas, Senior Communications Officer, Stop TB Department, WHO in planning and developing messages for the media and high-level meetings.

This has been mainly around the following events or activities:
- World Tuberculosis Day
- UK advocacy tours by TB activists and experts
- UK parliamentary delegations to Bangladesh (2008), India (2004, 07, 09), Kenya (2005, 06), Malawi (2009), Rwanda (2006), South Africa (2008) and Ukraine (2006)
- The declaration in 2005 by African Health Ministers of the TB emergency in Africa.

Key opportunities for generating media
- World TB Day events
- Activist and expert UK advocacy tours
- Africa TB emergency
- Parliamentary delegation to Kenya and other countries
- Grassroots letters to the editor

The media that was generated by the campaign around the declaration by African health ministers reached over 60 million people in Africa as well as a large audience in the UK.

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Parliamentary delegations: taking MPs to the problem

The delegation

The first parliamentary delegation was to Kenya with a cross-party group of MPs representing the three major political parties in the UK. It was important that the delegation was cross-party in order for it not to be seen as 'party political'. The delegation included four MPs: Andrew George MP (Liberal Democrat); John Barrett MP (Liberal Democrat); Julie Morgan MP (Labour) and Nick Herbert MP (Conservative).

Purpose and activities

The overarching purpose of the trip was to educate the MPs about the scale of the TB problem in Kenya, what was being done and what else was needed. The trip was timed to tie in with the declaration of TB as an emergency in Africa – as well as the Global Fund replenishment meeting in London.

Meeting with and talking to people delivering TB programmes as well as Ministry of Health officials was an important element of the programme. There were field visits to hospitals, clinics and to community TB programmes. Meetings with the National TB Programme (NTP) manager Dr Chakaya, health workers, patients, DFID, the UK High Commissioner and Kenyan media were also organised.

The media work was particularly exciting and included live radio interviews, one-on-one interviews with journalists, and a press briefing – attended by significant numbers of media, including major television stations. The media coverage helped leverage meetings with Ministry of Health officials which until that point RESULTS, DFID and the NTP manager had failed to get.

After the field visits – and shocked at the low level of support for TB at all levels (outside of the NTP) – the MPs became real advocates for TB at meetings with DFID, with media and with the Kenyan Ministry of Health.

It should as an important caveat be said that these interventions by MPs were all cleared with the NTP manager.

Outcomes

The delegation to Kenya clearly created political awareness of the TB problem and helped to facilitate RESULTS' work in the UK as well as in Kenya.

"…the whole experience has really brought home what people in Kenya lack and that TB is not a priority. Everyone we discuss TB with has always had it at the bottom of the list and we have to bring it into the discussion." Julie Morgan, former UK MP

Immediate actions planned by the four MPs as follow-up included:
- A letter to Secretary of State for International Development Hilary Benn and a request for a meeting
- An Opinion Editorial to be submitted to the London Times
- Presentations at party conferences.

In the longer term MPs planned to:
- Brief their parliamentary colleagues when Parliament resumed
- Raise questions in the House
- Generate further media around TB
- Ensure TB stays a political priority.

All of which they did. In addition, since then they have also formed an All-Party Parliamentary Group on Global TB, which now has over 60 members.

↘ **The group have also published several significant reports, including** '*Scaling up the UK's response to the Global TB Epidemic: An Agenda for Action*'. **Further examples of what the APPG on Global TB have produced are shown in Resources Section 5, Skill 1.**

The group has also gone on to help form a similar parliamentary group in the Indian Parliament. They have also actively engaged with the media at home and abroad.

Working with patient advocates

The bedrock of all RESULTS' work in developing political champions has been their 'patient advocates'. Lucy Chesire, a clinical nutritionist from Eldoret, Kenya, already mentioned, is one such advocate.

Lucy's HIV status was revealed to her in 1992 and she became the first female health professional to publicly announce that she was HIV-positive. In 2000, she developed TB – coughing, night sweats, weight loss. An X-ray revealed TB in the chest and later in the lymph nodes, and she underwent knee surgery and spent seven months in hospital.

Driven by her harrowing personal experience of HIV–TB co-infection, Lucy began to speak out. She became known to RESULTS and was invited to the UK on an advocacy tour.

Lucy spoke at meetings organised for her by RESULTS. These were with Ministers, NGOs, one-on-one meetings with MPs and were to inform, educate and influence the thinking and action of these on TB and TB–HIV.

RESULTS organised recorded and live TV and radio interviews on BBC World Service. They prepared briefings and coached her, but it was her personal story and what should be happening to control TB–HIV co-infection that was at the heart of her message.

Lucy also visited the Prime Minister's office at No.10 Downing Street where she delivered a personal letter to Tony Blair, Prime Minister at the time.

Lucy is now a leading patient advocate and 'TB champion', speaking out on the global stage at international meetings and influencing politicians and other decision-makers in many countries.

Of particular note, and a significant achievement for Lucy and the African TB community, was Lucy speaking out at a meeting of African Ministers of Health where she called for TB to be made a higher priority.

Ministers responded by declaring for the first time that TB was an emergency in Africa. This became world news – a remarkable achievement for a nutritionist from Eldoret in Kenya!

Photo courtesy of RESULTS UK.

↘ Photo: **Lucy Chesire** (middle)**, TB advocate and champion from Kenya, hand delivers a personal letter to the UK Prime Minister's residence.**

Suggested activity

1. List the decision-makers you would like to work with in your country.
2. How would/could you approach them?
3. What methods would you use to:
   • Engage them
   • Educate them
   • Inspire them into action
4. What opportunities could you use or create to generate media coverage on TB/MDR-TB?

End note

1. RESULTS UK exists to create the political and public will to overcome global injustices. It is a grassroots advocacy organisation that empowers people to take effective action to bring about change.
   ↘ **www.results.org.uk**

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Skill 2: Developing messages

In this section we define what key messages are and provide the nuts and bolts to creating them.

Here we give guidance, information and tips on developing key messages. The methodology for packaging information in the form of a press release is covered in Skill 9.

Participants should be able to formulate key messages and use them in professionally structured briefings and press releases and briefings etc.

What is a key message and what role can it play in advocacy?

Key messages are essential tools in all our communications work and an important means to an end. They are targeted to get information across to key audiences in order to effect change.

We need to identify key messages, distil the essence of what we want to say about a global health problem and/or what needs to be done about it.

We need to reinforce them in whatever we write and say. They should be at the core of our writing and speaking – effective communication which will open doors and help us persuade and convince the individual and/or audiences we are trying to reach.

Key messages are what we want an individual or audience to remember and react to. They get to the heart of the issue without lengthy explanation or qualification. They are essential to informing, inspiring and motivating others. They assert our viewpoint and opinion – and are best backed up with evidence and case studies.

They stimulate an individual or audience to ask 'How?' and 'Why?' and get an audience curious about what we have to say.

> We need to identify key messages, distil the essence of what we want to say about a global health problem and/or what needs to be done about it.

By prompting people to ask questions, they can get an individual or audience engaged in an issue. Curiosity is the first step to participation and strong messages will leave the reader/listener with a lasting impression and motivate them to take action on an issue.

Use accurate information, get your facts right

As with preparing good briefing material, it is essential to make sure you use accurate information when developing key messages.

If what you are talking about is not found to be factual, then the impact of the key message will be lost and your credibility as an advocate damaged.

Always use information from a reliable source that can be backed up, e.g. statistics from respected bodies such as the World Health Organization or public health statistics.

How to develop a message

The first step to developing strong key messages is to ensure you are clear about your advocacy objectives.

There may be several issues you want to address. However when creating your key messages, it may be best to package each separately to avoid confusion.

There are some basic rules to remember for creating and delivering key messages, whether written or spoken, for an individual or larger audience.

Key messages should be:

- CONCISE: Avoid jargon and acronyms.

- ACTIVE: Make every sentence active rather than passive.

- POSITIVE: Talk about what you can do, not what you can't

- SHORT: One memorable sentence that takes no longer than 5 seconds to say.
  For example: *"Without proper treatment with anti-TB drugs, approximately 90% of people with HIV die within three months of becoming sick with TB, even if they receive anti-retroviral treatment".*

- SPECIFIC: Address a particular challenge.

- TARGETED: Address a particular audience.

! Remember the big three!

1. Three key messages: Don't try to include more than three key messages or what you are presenting will lose its impact.
2. Use three parts to your presentation: a beginning which must grab your audience and introduce the topic; a middle which gives background to your campaign and evidence for what you are saying etc. and a conclusion, summing up the key points.
3. Keep to three examples – you and your audience will be more likely to remember them.

Sound bites

Sound bites are short, concise messages, crafted for use most commonly in media interviews, though they can be used in meetings and presentations.

Sound bites should capture and communicate the one key message you want to leave with the audience if they remember nothing else, and may be even more concise than your set of key messages.

Some examples of TB sound bites are:
- 'It doesn't take a miracle to stop TB'
- 'TB and HIV are double trouble'
- 'TB is a ticking timebomb'.

Try to repeat a sound bite at least twice during an interview with the media.

✎ Suggested activity

1. Currently which are the three key messages relating to TB that are most important to communicate in your country?
2. Write them down
3. Choose one and create a 10-second sound bite

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Skill 3: Preparing informative briefing material

There are many information sources you can use to shape your advocacy. Any messaging or materials will benefit from consulting some or all of the sources below:

The Internet

Use a reputable and thorough search engine. 'Google' is particularly good as it allows you to search under a number of different terms. You can also search for images and journal articles.

When using information from any of the sources your search engine highlights, always check when the piece was produced and by whom. Text is often not dated, which can be a problem if you want to cite information and particularly data.

Make use of the hundreds of official websites which relate to your activity. Websites such as the World Health Organization have a wealth of up-to-date information and are a verifiable source. Others, such as the Stop TB Partnership, UNICEF, the World Bank and the Global Fund, have a vast amount of useful and accurate information, which you can access freely.

If websites do not provide the information you are looking for, there is often the option to 'Contact us'. This is a facility provided through the website which allows you to send an email to a member of staff at the particular institution and can often be a useful way of retrieving information for use in your advocacy.

Publications

Most NGOs, government departments and institutions produce a number of reports and publications each year.

By using official sources for your briefing material, your information will be verifiable and easy to reference.

Photo courtesy of Advocacy Partnership.

Newsletters and newspapers

Most national and international newspapers have websites which allow you to search for recent and archived articles.

Many newspapers also have an email alert system where you can register to be sent articles that include your search terms. For example you could register to be sent all articles that refer to the 'Global Fund to Fight AIDS, TB and Malaria'.

There are also newsletters and e-circulars which you can sign up to by checking on relevant websites. For example Global Health Reporting and the Stop TB Partnership have regular emails which you can sign-up to receive.

NGO community

By being active in your local and national NGO community you can have input into campaign development and keep abreast of what is coming up on different NGOs' agendas.

This provides an opportunity to collaborate and share information where appropriate. Many individuals within NGOs are experts in their field and useful to communicate with. They may also have connections with others in government departments and Parliament.

> Many individuals within NGOs are experts in their field and useful to communicate with.

Personal contacts

An effective advocate will build up a database of contacts. Always remember to exchange business cards with people you meet. They may be new and useful sources of information or become a trusted contact with whom you can discuss latest advocacy ventures.

Remember, 'hearsay' and 'off the record' information should not be used as a basis for your messaging. This information can't always be verified, you will often not be able to name your source and you may give your audience an easy way to undermine or discredit your advocacy efforts.

Suggested activity

Using the headings above, list the reputable sources of information in your country you could use for your advocacy.

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Skill 4: Speaking powerfully

How to convey a message

Communicating well – whether you are telling stories, giving factual briefings or delivering sound bites for the media – is absolutely crucial to getting your messages across to the audience you want to influence.

Most ways of communicating have value – but some are more appropriate for certain settings and audiences than others. For example, a detailed sentence full of statistics would not be effective for a 10-second sound bite.

Speaking powerfully – becoming a good spokesperson – is what we are trying to achieve in order to influence change around TB.

There are people in the world who we all know are great spokespeople. What they have to say is memorable, they have a strong message and their delivery is powerful.

What makes a speech powerful

The elements of a powerful speech can be demonstrated in a series of video clips of some very different spokespeople with very different messages.

> ↘ See links to media clips in Resources Section 5, Skill 4 Powerful speaking.

Suggested activity

If you can, take a look at the media clips and make notes.
What did you notice about their delivery? How were they being? What phrases worked?

Particularly note the following three:
1. Oscars Ceremony where Marlon Brando was given an Oscar for his role in the film 'The Godfather'.
2. US President Ronald Regan at the Brandenburg Gate in Germany.
3. UN Special Envoy for AIDS Stephen Lewis at the International AIDS Conference, Toronto.

Tactics for reaching your audience, getting your message across

If you have looked at the media clips mentioned above you will have noticed the tactics used by all the speakers to get their speech noticed – to have the audience remember what was said.
- Marlon Brando – the tactic of the 'unexpected'.
- Ronald Regan – the tactic of using a public platform to directly appeal to the person to influence.
- Stephen Lewis – passion and oratory to leave the audience spellbound.

Storytelling

Why tell moving stories? Because moving stories captivate us and reach us as human beings. They can make us laugh and they can make us cry.

The following brief examples demonstrate different ways of getting information across and why stories that are personal and real are so powerful.

The first two examples are taken from documents of respected institutions.

Example 1

"UNICEF recently reported that, for the first time in history, the number of children dying each year of largely preventable causes fell below 10 million in 2006.

"However that still means 26,500 children die each day from preventable illnesses like diarrhoea, pneumonia, measles, and malaria."

Example 2

"South Africa is one of the 22 High-Burden Countries that contribute approximately 80% of the total global burden of all TB cases. South Africa has the seventh highest TB incidence in the world.

"During the past ten years the incidence of tuberculosis has increased, in parallel to the increase in the estimated prevalence of HIV in the adult population. This has resulted in the increasing recognition of the problems posed to public health by TB."[1]

The next two examples are personal testimonies.

The first from Winstone Zulu, a Zambian, and the sixth of 13 children. Winstone was diagnosed HIV-positive and became the first person in Zambia to publicly acknowledge his HIV-positive status. In 1997 he began to develop symptoms of tuberculosis, though his doctors were slow to diagnose TB.

Example 3

"I had pains in the chest, night sweats, weight loss, loss of appetite. I went to the hospital where they did a chest x-ray and sputum test. There were lots of people coughing in the clinic. There was even a power cut. When I went back after a week they told me the tests indicated I didn't have TB.

"My younger brother had TB and said that the symptoms I was experiencing were very similar to his. He gave me drugs prescribed for his TB which I took and I immediately started to feel better.

"Within two to three days I'd experienced a big change. I went back to the hospital and told them that in fact it was TB. Four months later they told me they had just found TB from my tests. I could be dead now if I'd waited for them to diagnose it.

"My brothers Erasmus and Christopher got tuberculosis at around the same time. It was so tragic,

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[continued] Erasmus died on the 7th December 1990 and his wife died the following day, and then Christopher died a week later.

"And then there was Shadrek, he was the eldest of all of us. He worked for BP, he was a truck driver. He left six children. He died in 1996 from tuberculosis as well. His wife died the following year.

"Danny, he was the youngest. Danny was a really good musician, he used to work in South Africa. Then he came back and we started living close to each other, we became very close. He died in 2003.

"They shouldn't have died. TB is preventable, whether people are HIV-positive or not. TB treatment gives patients more time. If my brothers had survived TB they might have lived long enough to access HIV drugs like me."

The next example is from a Peace Corps volunteer:

Example 4

"My years as a Peace Corps Volunteer in Niger taught me many things — some of them profound, and some of them tragic.

"One of the tragic lessons I learned was that the number of parents who experience the pain of needlessly losing a child is not equally shared around the globe. This lesson became particularly poignant the day that Issa, my blacksmith friend and neighbour, walked into my mud hut with panic and shock written on his face.

"Please come and see my baby – she's sick and doesn't even know who I am," he managed to say. When I arrived, the beautiful baby was listless, but breathing. As I watched her and stroked her black hair I could see the life ebbing out of her, her breathing slowing until it stopped.

"I immediately crouched on the floor, put two fingers on her sternum and tried frantically to breath life back in to her, as Biba and Issa looked on in horror. I knew there wasn't a doctor or a health facility for miles that could help me, so I just continued working on her. The infant finally expired in my arms and Biba wailed.

"I never found out why she died. But I knew that she never really had the same chance to live a full life as those who have access to vaccinations, clean water, and medical facilities. She was one of the 10 million preventable child deaths that year, and I will never forget that day."

All the examples are powerful, but the third and fourth put a human face on the problem in a way that is poignant. This is what moving stories do; they take something that can seem abstract and impersonal and turn it into something very personal. A moving story softens the listener and appeals to their humanity in a way that facts alone cannot.

How you can use moving stories

You can use moving stories to help community members, the media and Members of Parliament to really connect with and be touched by both the problems of poverty and the solutions.

A good example of this is when RESULTS US grassroots activists from North Virginia met in a face-to-face meeting their member of Congress, Jim Moran, and told him a story from the New York Times.

The story was about a six-year-old boy sold into indentured servitude for US$20 per year by his parents because they couldn't afford to feed him. The activists went on to explain how microcredit would allow parents like these to keep their children at home.
As they told the story, Representative Moran moved forward in his chair and said; "Wow, I need more of these. This puts a human face on it. I will be speaking to 1,000 women at a conference next week and I want to use this story."

At that moment, the RESULTS activists became Representative Moran's speechwriters!
Powerful storytelling is very different from having to memorise a set of statistics. It involves the listener and leaves them with a memory of an event or person that will be difficult to forget.

All decision-makers, whether they are Members of Parliament, Ministers, or journalists, are people! They remember stories that move them.

Listen to others and learn. Tell their stories or create your own. Stories are key to changing hearts and minds, and a critical tool in advocacy.

All decision-makers, whether they are Members of Parliament, Ministers, or journalists, are people! They remember stories that move them.

Suggested activity

1. Create your own TB story – one that tells the story of your own TB (if applicable) or one that you have heard someone else tell.
2. What are the key elements that make it powerful?

End note

1. Tuberculosis Strategic Plan for South Africa 2007-2011. Department of Health, Republic of South Africa.
↘ **http://www.info.gov.za/view/DownloadFileAction?id=72544**

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Skill 5: The one-minute message

In many advocacy situations you may have to deliver a concise, informative and memorable message in just a minute – often without any time for 'preparation'.

You may be called by a journalist and need to respond immediately – and if you can't keep them on the line, listening to what you have to say, the opportunity may be lost.

You may bump into a key decision-maker and want to take advantage of that opportunity and leave them with something memorable about the issue that concerns you and even a request for action.

The key here is to plan ahead for such events and develop a number of one-minute messages that could be delivered as they are, or enhanced and padded out with more information if the situation allows for that.

RESULTS developed a methodology for putting together a one-minute message (the laser talk) – a sharp, concise message – around the word EPIC.

↘ Photo: **Lucy Chesire** (left)**, TB advocate and champion from Kenya, meets briefly with a member of the Scottish Parliament. The one-minute message is a useful technique to prepare for and use in short briefings.**

Key components of a laser talk – EPIC

E	ENGAGE	What is the problem to address?
P	PROBLEM	Some more information on the problem.
I	INFORM (ILLUSTRATE)	A few examples of impact or cost etc.
C	CALL TO ACTION	A call to action (what should be done). The opportunity it could provide if realised (e.g. lives saved).

Here is an example of a one-minute message developed around MDR-TB:

Multidrug-resistant TB (MDR-TB) is a dangerous form of TB, resistant to the two most powerful anti-TB drugs available, and caused by inconsistent or incorrect treatment of TB.

MDR-TB can be treated – but the treatment costs are high.

But if MDR-TB is mismanaged then this can lead to extensively drug-resistant TB (XDR-TB)

Both MDR-TB and XDR-TB can be spread from one person to another.

In 2006, an outbreak of XDR-TB in KwaZulu Natal, South Africa killed 52 of 53 people affected – 70% within one month.

Within two years XDR-TB has increased five-fold to 55% of drug-resistant cases. It is now found in every province in South Africa.

Each year nearly half a million people will develop MDR-TB – and many of them will be in South Africa. If XDR-TB really takes hold then the costs to the country will be huge.

It is vital that South Africa strengthens and expands all its TB programmes across all provinces, especially those with the highest incidence of MDR-TB, to prevent further drug resistance.

Resources are needed immediately at provincial level in South Africa to support better diagnostics, lab strengthening and patient follow-up – in order to stop the spread of MDR-TB and the threat of XDR-TB.

MDR and XDR-TB do not need to be a death sentence – full implementation of the XDR and MDR-TB Global Response Plan will save the lives of thousands of African patients.

In 2006, an outbreak of XDR-TB in KwaZulu Natal, South Africa killed 52 of 53 people affected –

70%

within one month.

Suggested activity

1. Now create your own one-minute message on TB/MDR-TB using the EPIC process.
2. Try speaking it to a friend/colleague to hear their feedback.
3. Refine for use.

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Skill 6: Effective meetings

Meetings with high-level decision-makers are an everyday occurrence for anyone doing effective advocacy.

This is a key part of building and nurturing your relationship with decision-makers and essential if you are to succeed with your campaign.

Aim of meetings

The main purposes of an effective meeting with a high-level decision-maker are to:

- Communicate passionately about an issue that concerns you
- Generate partnership, find out what you want to know and bring the decision-makers on side
- Make specific 'asks' or requests and move the action forward.

Key components for an effective meeting

Before the meeting

1. Make sure you are clear on the following:
- Who you are meeting with – use information from websites, other organisations, bios, committees they sit on etc.
- The reason for the meeting – what specific 'asks' you will make and what support you can offer to achieve that ask. What outcome do you want?
- What is the wider opportunity – how will your meeting contribute to the bigger campaign? (For example. gathering information for use in the future, building relationships, practising speaking for your advocacy work etc.)

2. Be prepared:
- Create an agenda and decide who will cover which parts.
- Ask each person speaking to prepare a one- to two-minute message of what they want to say.
- Practise speaking with at least one other, be clear and concise but don't be afraid to be passionate!

3. Choose a manager and note-taker:
- Choose one person to manage the meeting and ensure it stays on purpose and that all requests are covered.
- Assign someone to make notes – especially of commitments made and follow-up action.

4. Be inspired:
- Meet briefly right before the meeting and have each person speak why they care about the issues they will be raising and why they are going to the meeting.

At the meeting

- Connect with the person you are meeting with, by asking them to share their commitments and aspirations. Share your own.
- Acknowledge the person you are meeting with for what they have accomplished. Thank them – maybe for meeting with you.
- Be concise – make specific clear requests and ask for an answer.
- Summarise your requests in two or three key points that will take no more than ten minutes.
- Ask what else they think could be done.
- Be prepared to summarise the other side of the argument – do your homework and have speaking points ready to defend your requests. Don't be aggressive. If you don't know the answer to a question, promise to find out – and do keep your promise.
- Make the issues real – share your personal stories.
- Paint both the small and big picture – the micro and macro. Have someone share how they have been affected personally, then have someone speak to the bigger picture and include national and global statistics and impact.
- Thank the person you are meeting with and make sure all next steps and follow-up actions by the person and yourselves are voiced before the meeting concludes.

Follow-up to the meeting

- After the meeting immediately send a thank you note and key points to be followed up.
- Take follow-up action and organise another meeting to report back.

↘ Photo: **Winstone Zulu (left),TB patient advocate from Zambia, meets with the Japanese Prime Minister.**

Photo courtesy of RESULTS UK

Suggested activity

Make a list of all the high-level decision-makers you would like to meet with.

Choose one and write:
1. What you know about them already.
2. What do you need to tell them?
3. What action do you want them to take?
4. When will you meet them and who will you take with you?
5. What outcomes would you like in the short and longer terms?

Skill 7: Active listening

Active listening will be particularly useful when working in coalitions, e.g. when creating your advocacy plan, as well as when in conversation with decision-makers you want to influence.

Often people listen selectively to what they agree with or are comfortable with. However, in active listening, the listener keeps an open mind and recalls what is being said, irrespective of whether he or she agrees or not.

Active listening is a communication skill in which the listener in a conversation follows closely what is being said and gives feedback to the speaker using verbal and non-verbal expressions. Active listening takes place when a speaker realises that he or she is being listened to. Active listening liberates the speaker and unleashes creativity.

Unlike selective or discriminatory listening, active listening is an approach that strengthens the capacity of individuals, opens up a host of new ideas and activates the knowledge and resources of each individual. It favours sharing and the acceptance of new and diverse perspectives and mutual learning. It also limits exclusion.

In a 'group process', active listening demonstrates that group members respect each other's opinions. It recognises the contributions of vulnerable groups, including people living with TB, women and youth.

Objectives

In your advocacy work it is important to allow and enable fellow advocates to:
- develop their active listening capacity;
- listen and accept perspectives that are different from their own.

Elements of active listening include:
- Maintaining eye contact and following the speaker with your eyes.
- Not showing signs of disagreement or being frustrated with a speaker's opinion.
- Observing and acknowledging non-verbal expressions.
- Paraphrasing to confirm that you understood what has been said.

Suggested activity

This is an activity to conduct with your advocacy colleagues.

1. Bring participants into groups of five or six people.
2. Write five 'controversial issues' on the flipchart. For example:
   - Talking about TB stigma with government officials should be encouraged.
   - Locking up MDR-TB patients should be mandatory.
3. Ask participants in groups to reflect individually and, only after that, write down their responses and perspectives.
4. Ask participants to read their responses and share their perspectives with other group members.
5. After everyone has expressed their views, ask each group member to remember what they heard from others.
6. Pay attention to whether people retain only what they agree with, or if they also remember what they do not agree with.
7. Ask those who want to clarify their perspectives and ideas to do so and allow others to contribute.
8. The group is encouraged to reach common perspectives and consensus if possible or to recognise that there is no consensus and that diversity is a reality of their group.
9. Ask participants to give a detailed description of how to show respect for and take into account everyone's perspective during conversations.
10. Ask each group to identify three key elements of active listening and respect for diverse perspectives.
11. The facilitator summarises by sharing the key elements in plenary. She/he clarifies that active listening includes not interrupting the person who is sharing his or her perspective and ensuring that each viewpoint is respected and considered as part of the group's reality, even if everybody does not agree with it.

Skill 8: Working with the media

People – including decision-makers – usually believe what the media has to say, so getting your message right and having that reported accurately is a critical factor in your advocacy work.

The first vital step is to build relationships with the people who work in the media and engage them in your advocacy work. A good relationship with even one journalist is going to dramatically impact the outcome of your campaigns.

Get to know which journalists write on which areas and issues, e.g. international development, global health. The more you know this, the more likely you are to be able to pitch an idea to them effectively.

Keep a profile of their articles – news and opinion articles – over a period. See what kind of stance they take on a particular issue and if there is a way you can offer something to them which will fit with the kind of areas they write on.

It is good to establish what the 'editorial process' is at the particular media you are targeting. Find out when journalists have their editorial meetings, what are their deadlines and when is best to contact them.

Remember if a journalist trusts you, they will come to you as a good source of information.

Tips for getting your message/story used

Ask yourself:
- Is it news?
- Is this the right time?
- Who is the best journalist to take this story to?

Prepare what you want to say.

Create a press release.

Write a piece for the paper.

↘ Photo: **Lucy Chesire** (right)**, TB advocate and champion, during a radio interview.**

Photo courtesy of RESULTS UK

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Developing a media strategy

The first step is to develop a coherent media strategy. This should include:
- The issue/problem you want to address.
- Who you are trying to reach – who is your audience or audiences (and what media will be most appropriate to use)
- What messages you want to communicate.
- What media you will use to reach your audiences – communication channels (and all their contact details)
- What barriers there are – e.g. competing problems/messages in your region, country, world
- Your timeline
- A plan of activities
- What material/resources will you need – one-minute messages, briefings, reports, photographs, speakers
- Who will lead the communication.

Do your research

People who work in the media are generally very busy, with competing stories and deadlines to meet. You will need to consider:
- What are their constraints – are they looking for a local angle or a big story?
- What specific interests does a journalist have? Who is the health reporter? What do they already know about your issue and what do they need to know? What news can you tell them?
- What deadlines do they have? Editorial meetings, going to press?
- What schedules are they working to and how long does the production/publication process take?
- When are their publication days? Are they daily, weekly or monthly publications? What is the programming schedule?

Suggested activity

1. Develop a list of key media outlets and journalists working in your country.
2. Develop a plan of action for engaging them in TB/MDR-TB.

Skill 9: Preparing a press release

This is the usual way to distribute your news or story to journalists in many media outlets. Its objective should be to inform the journalists of your story or event and be complete enough to be used with little or no change. A press release could also help them write a piece on the issue.

The main reasons for producing a press release would be to:
- Draw attention to an issue
- Provide background information on the issue
- Provide information about an event or action taking place, or a report to be launched.

Content of a press release

Headline: Write a striking and catchy headline that helps the journalist understand the story and what the news is.

Opening statement: The first sentence should include the most important facts of the story:
- WHO
- WHAT
- WHERE
- WHEN
- WHY.

First paragraph: Expand on the headings above, including the most important facts first and the least important at the end.

Style: Use short, 20-word sentences and short two- to three-sentence paragraphs. Mimic the style of the paper you are trying to reach.

Presentation: Use or create headed paper for a professional image. Lay out the text well, in double spacing on one side. Include the date, name of a contact organisation and contact name with telephone, fax and email address. Include an embargo date and time if necessary. Provide brief background notes for the journalist.

Photographs and other supporting material: These should be of key people and places mentioned in your release in the format specified by the publication.

Quotations: These are very useful for bringing that personal touch and for highlighting the comments of well-known or key people.

⬊ **A sample Press Release is shown in Resources Section 5 Skill 9.**

Suggested activity

1. Create a press release around a key issue/event in your country.
2. Ask others for their feedback.

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Skill 10: Writing for the media

Most media are interested in the opinion of their readers – their target audience. They usually accept pieces of opinion on most topics.

Newspapers print follow-up letters and reader feedback on their own stories, opinion on major events and/or important issues, and/or an exchange of readers' points of view on issues raised by other readers.

The upsurge of the internet means there is far more space now for comment and opinion, much of which is published online.

Different newspapers will have a different political stance, so it is important you establish who is reading which papers and which will most effectively reach the audience you wish to talk to.

Get to know the local/national newspaper you want to write for. This will help you to shape your message in a way that is meaningful for readers and increase your chances of being published.

Opinion editorial articles

Most newspapers print opinion editorials (OpEds) or guest columns. An OpEd is an expression of opinion rather than a statement of news/fact. Although the style varies in different countries, OpEds tend to be lively, provocative and sometimes controversial.

They are a powerful way to reach policy-makers about the issues of concern about a particular health issue or disease and to inform communities about why they should care.

OpEds are usually around 1000 words. This may be written by a journalist on the newspaper or you may write it yourself. It is best to contact the newspaper first to request their guidelines. Speak to the editor of smaller local newspapers for this information or on larger international newspapers to the editor responsible for OpEds.

You may also pitch an OpEd in the name of a well-known advocate to a newspaper. You may then be required to 'ghost-write' the article. High-profile guest columns are very popular with newspapers.

↘ **An example of an OpEd is shown in Resources Section 5 Skill 10.**

Letters to the Editor

Newspapers and magazines almost always have a Letters Page that gives readers the opportunity to express their views or correct previously published information they feel to be inaccurate or misleading.

Letters are widely read and provide an excellent opportunity to promote a cause and/or organisation. They should be short, concise and make their point in a few paragraphs in a punchy and passionate way. Editors can and will edit your letter. Letters of no more than 100 words can be very effective.

A letter should aim to make one main point and end on a challenging note, for example with a call to action. They can be signed by several signatories from various organisations which increases their impact.

Write the letter and include your details so that the editor can contact you for clarification if necessary. If a letter is responding to an article carried in a daily newspaper, it is important to email or deliver it to the paper within a couple of days.

↘ **Sample letters to the editor are shown in Resources Section 5 Skill 10.**

Letters should be short, concise, and make their point in a few paragraphs in a punchy and passionate way

Suggested activity

1. Think of a well-known advocate to guest write a newspaper column.
2. Write down the main points you would include and the pitch you would make to a newspaper.
3. Get feedback from others.

Photo: ©iStockphoto.com/Ekaterina Monakhova

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Photo courtesy of RESULTS UK.

Monitoring and evaluating advocacy work

advocacypartnership

Monitoring and evaluating advocacy work

Monitoring[1] and evaluation[2] (M&E) of advocacy efforts is a relatively new area of work carried out by civil society organisations (CSOs), often as a requirement from donors. For this reason, this section has drawn on materials available online such as the BOND Advocacy Guidance Notes[3] and ActionAid's Monitoring and Evaluating Advocacy,[4] and adapted the content to a TB context.

M&E of advocacy work can be challenging for a number of reasons. Determining how a myriad of activities have effected change can be difficult.

In all evaluation, the issue of attribution is one of the hardest things to deal with. Questions you might want to ask to help you assess impact and attribution are shown below.

Audience	Client (i.e. TB patients, affected communities and those who would benefit from advocacy work)
Who was supposed to hear the message?	If clients are not already working with the NGO how are they contacted in order to ensure that the NGO is acting appropriately on their behalf.
Who has heard the message?	To what extent have NGOs who are involved in advocacy projects explained their advocacy activities to poor people they are working with?
How did they interpret the message?	Has there been any attempt to get these people to rank advocacy work versus other activities that they might see as more relevant?
How was it different from other messages?	What effort has been made to provide feedback to the same people about the results of advocacy work?
What did they do in response?	To what extent do people feel more confident about their capacity to advocate on their own behalf?
Have they heard of the sender?	What effort has been made to seek their assessment of results and their confirmation of assumed impact?
How do they differentiate the sender from others who might be sending similar messages?	

It is very difficult to know precisely what has contributed to policy change and what impact those changes have on the ground. The main reasons it is difficult to monitor and evaluate advocacy are:

- Complexity of determining cause and effect.
- A moving target – policy and programme change happens in an external environment which may change, necessitating a change in how you monitor and evaluate your work.
- Difference of opinion – what constitutes a successful outcome for one group may not be seen as such by another.
- Timescale – advocacy is a long-term activity and change may only be seen over a long time period.

The above, in addition to country specific issues, poses a real challenge in developing useful methods to support meaningful learning in the area of advocacy work.

↘ **These challenges are addressed in more detail in Resources Section 6.**

Why do we need to monitor advocacy?

It is important to build trust and understanding with donors. Part of that process means being able to demonstrate that we are delivering on our investments.

We need to be able to produce credible reports for donors, funders and managers which show we have made good use of their inputs to achieve certain outputs.

We need to be able to develop reasoned arguments about how these activities contribute to our long-term objectives and, in the case of TB response, how they complement TB control efforts (e.g. availability of public funds, political commitment, supply of drugs, diagnostic tools etc.).

Challenges

What should we be monitoring?

There are a range of activities and constituencies which CSOs can undertake to monitor and evaluate. Some of this will be 'soft' monitoring, including behaviour change; other monitoring and evaluation will be based on 'hard' data (e.g. official documents, speeches, surveys, newspapers etc.).

Monitor your target audience

- Record and observe changes in the rhetoric of your target audience.
- Notice what they are saying about the subject matter of your advocacy work.
- Try and see if they are moving closer to your position, adapting to or adopting any of your language or philosophy.

Monitor your relationships

- Record the frequency and content of your meetings (formal and informal) with external sources and target audiences.
- See if you are discussing new ideas.
- Ascertain if you are becoming a confidante or a source of information and/or advice.

Monitor media

- Count the column inches on your issue and the balance of 'for' and 'against' comments.
- Count the number of mentions for your organisation.
- Analyse if media is adopting your language.

Monitor your reputation

- Record the sources and numbers of inquiries that you receive as a result of your work.
- Are you getting to the people you targeted?
- How and where have they heard of your work?
- How accurate are their preconceptions about you and your work?

Monitor public opinion

- Analyse the climate of public opinion through telephone polling, or commissioned surveys or focus groups.
- There are lots of online surveys, e.g. Survey Monkey, that could be useful. This can be very easy to set up and gives a good indication of how people are reacting to a campaign or issue of concern.

↘ **See: www.surveymonkey.com**

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How to evaluate impact

To evaluate the impact of your project you need to be clear about the model or process you are trying to follow and decide on what information is available to you to assess each part of the process.

Recent work suggests one way of thinking about the process is as an 'impact chain':

Build awareness ▶ **Change policy** ▶ **Measure impact on people's lives**
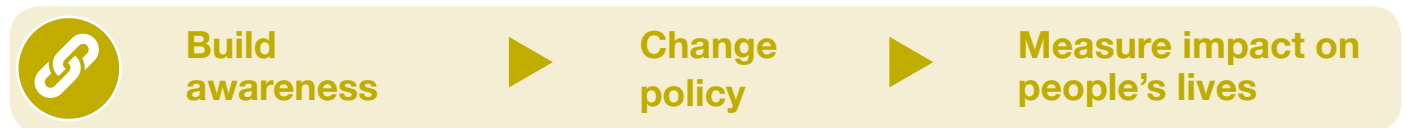
In each phase there are policy and grassroots activities, both of which need to be monitored. The relationship between these activities is also important, and the more integrated they are the more successful the project is likely to be. Grassroots activities are likely to involve capacity building. Below is an example of an impact chain from HIV/AIDS activists in Ukraine developing a campaign for Substitution Maintenance Therapy (SMT).[5]

Impact chain from HIV/AIDS activists in Ukraine developing a campaign for Substitution Maintenance Therapy (SMT)

SMT is an effective way of improving adherence to ART among people living with HIV who are injecting drugs, as well as preventing HIV among people who inject drugs. Availability of SMT in Ukraine was limited to a United Nations Development Programme (UNDP) funding for a six-month pilot project using substitution therapy medication, buprenorphine. SMT proved extremely challenging for many state agencies to accept. Although it formed part of the public health strategy, few people outside the international HIV community in Ukraine were committed to it. In addition, medical professionals dealing with drug dependency were reluctant to take on additional workloads and were concerned about the impact of SMT on existing treatment for drug dependence.

Build awareness > Partnership was formed by national and international civil society organisations, including the Ukraine HIV/AIDS Alliance, PLHIV network, the Clinton Foundation, the Open Society Institute, WHO and Ukrainian Institute of Public Health Policy, UNAIDS and UN Office on Drugs and Crime. Through meetings and national conferences, officials were introduced to international experience of implementing SMT, first buprenorphine that was already registered in country and then methadone, which is a less expensive drug and more suitable to scaled-up programmes.

Change policy > Following recommendations from those involved in the campaign a Presidential Decree was issued requiring the elimination of barriers to the scale-up of methadone-based SMT. It also established the Presidential Council for AIDS, TB and Drug Addiction.

Measure impact on people's lives > In May 2008 methadone-based SMT was introduced in Ukraine, however implementation was slowed down by continuous opposition to SMT within the public health sector. Once the GFATM gave an unacceptable rating for the Ukraine grant appraisal on SMT, the Minister of Health signed an order that made way for the scaling up of implementation. A 12-month monitoring exercise conducted by Alliance Ukraine, WHO and the Ukrainian Institute of Public Health Policy in 2008 demonstrated that SMT is a proven method for supporting PLHIV who are injecting drugs, through HIV treatment programmes.

Indicators, such as people expressing accepting attitudes towards TB and TB patients may help you to develop indicators in your own advocacy work.

Grassroots activities are likely to involve capacity-building activities. For example, different stakeholders will have different views on what impact entails. To get an overview of how successful your activity/ campaign has been, you will need to solicit the views of a range of stakeholders, i.e. beneficiaries, local people and their organisations, staff, targets, journalists and others.

This can be done using a variety of methods. For example:

- Surveys can provide an overview of what was achieved.
- Interviews reflect the perspective of different stakeholders.
- Participatory techniques such as 'ranking' or focus group discussions are useful for assessing the success of grassroots activities.
- Video can be an effective way of keeping the emotion and reality in the evaluation process.
- Case studies that draw on a range of techniques and are cross-referenced to avoid bias are a helpful way to provide useful lessons and present complex material. These can be done for specific projects, institutions or groups of beneficiaries.

Photo courtesy of Advocacy Partnership.

↘ Photo: **Participants in TB advocacy training in New Delhi, India discuss and review their advocacy activities.**

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Case studies

Sometimes one of the best and most cost-effective ways of understanding the effect of policy change or advocacy work relating to M&E is to produce a case study.

A case study can illustrate a specific area of advocacy and provide a 'qualitative', in-depth understanding of factors behind some of the more general, summarised data.

Although it should not be considered as representative of the whole situation, it can provide valuable information regarding:

- Impact of advocacy work from the point of view of stakeholders, policy decision-makers, affected communities etc.
- Examples of good practices (or lessons learned);
- Follow-up to previous case studies (in order to prove policy or behaviour change)
- Multiple case studies could be used for comparative purposes.

Case studies can be incorporated in reports as annexes, boxes within text and chapters.

Steps to conduct case studies

1. Define the purpose of the case study.
2. Decide selection criteria of case studies to be used and define clear components of the case study, e.g. outline whether the case study is an extreme example, a single example or a collection of case studies for comparative purposes, an example that had not been previously noticed, that is, new evidence etc.
3. Research data, which includes deciding how to obtain the necessary information to substantiate the case study arguments, as well as how to incorporate this data into overall study.
4. Develop data collection tools specific to the case study, e.g. interviews (structured and semi-structured), surveys, story-telling, field trips etc.
5. Define data to be collected, responsible parties and methodologies (either qualitative or quantitative methods).
6. Determine how data will be analysed.

The UK Coalition to Stop TB developed an advocacy tool, 'TB election Asks', in the run-up to the UK elections. The document, which was launched on World TB Day, urged a new UK Government to ensure that TB is made a priority within its domestic and global heath agenda. It called on all parties to review their plans in light of these asks. In order to illustrate the facts of TB (which are mostly reported in terms of numbers) and give a more personal touch to the document, a brief case study was developed. The case study was selected based on a number of different criteria including:

- Personal story (e.g. give a human face to numbers, estimates and statistics)
- A single story to illustrate a general situation
- A story to reinforce the need to address one of the TB election asks, in this case, the social determinants of health (e.g. abolition of user fees)

The case study incorporated as a box into the document was identified from one of the projects run in India by an organisation member of the UK Coalition to Stop TB. The case study was structured as a 'story-telling'. Organisations agreed to submit available case studies, which were then selected by a committee responsible for writing the TB election asks.

↘ **The Case Study can be found in Resources Section 6.**

Photo courtesy of WHO/TBP/Gary Hampton.

↘ Photo: **Mpila, a traditional healer and now a DOTS supporter, with one of his patients.**

End notes

1. Monitoring is the collection of information about a project over time. It seeks to understand what is happening.

2. Evaluation is an assessment of the project at one point in time, including the successes and failures. It seeks to understand what and why it happened.

3. BOND, Advocacy Guidance Notes.
   ↘ **www.innonet.org/client_docs/File/advocacy/bond_monitoring.htm**

4. Chapman, Jennifer. Monitoring and Evaluating Advocacy, ActionAid, 2002.

5. Successfully reaching injecting drug users in Ukraine. International HIV/AIDS Alliance, 2010.
   ↘ **www.aidsalliance.org/NewsDetails.aspx?Id=553**

advocacy**partnership**

Section 7

Resources mobilisation for advocacy work

Photo courtesy of RESULTS UK.

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Resource mobilisation for advocacy work

In many countries funds can be sought from NGOs, foundations and trusts etc. The key is that any organisation seeking funds for advocacy work must invest in researching potential donors and their interests and gain support for writing strong proposals.

The ability to mobilise resources is a valuable skill for advocacy work inasmuch as it is based on realistic goals to address particular advocacy issues. It will be particularly useful in:

- Seeking small grants from bilateral development organisations at country level. However donors may have their own agenda or attach conditions to their grants, which may conflict with an advocacy goal.
- Applying for international organisations grants or awards.
- Targeting private sector (e.g. pharmaceutical companies) concerns within their own communities.
- Tapping into available human and financial resources within organisations or networks.

↘ Photo: **Advocacy tour experts Bobbie John** (left) **from India and Mario Raviglione** (second left) **from WHO, meet with UK parliamentary and government decision-makers at an All Party Parliamentary Group on Global Tuberculosis meeting in London. Educating potential donors is critical in influencing resource mobilisation for TB.**

Donors

There is no short-cut when it comes to resource mobilisation, particularly for advocacy work. However donor agencies have become increasingly aware of the need to ensure sustainability of the results and outcomes of funded projects and programmes.

Advocacy can play a pivotal role in terms of scaling up and sustainability of TB control efforts. The challenge is to identify those like-minded donor agencies that recognise the complementary role of advocacy to TB control efforts and develop thorough TB proposals that clearly integrate advocacy as part of the strategy to achieve expected outcomes, rather than outputs.

TB activists and CSOs working on TB are encouraged to carry out research on potential funding agencies at the country level in addition to the few global agencies supporting TB control efforts.

It is important to find out what types of organisations the donor has funded in the past, how much it typically donated, and what is the nature of its current interests, which would be available on annual reports, country strategies etc.

In order to avoid donor control over the advocacy agenda or strategy an organisation should seek support from donor agencies that match with its advocacy objectives.

$ Donors are generally interested in:

- A well-run and efficiently managed organisation or effort
- Financial stability and budget information
- Examples of successful efforts
- Good strategy and a reasonable chance of success
- Traits that distinguish the network from other organisations in the same field
- Why the work is important and necessary
- Achievements associated with any previous contributions
- Information on the network's activities and successes; if the network is new, information on its strategy and goals.

Certain types of information, language and presentation styles will elicit a positive response from funding sources.

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Main international funders

DFID

- Different funding schemes, either thematic or regional.
- Advise CSO and activists to visit country office websites and country assistance plans.
- The Effective Health Care Research Programme Consortium (EHCRPC) has carried out case studies on TB.
- Website does not inform about direct support to southern CSOs.

Bill and Melinda Gates Foundation

- Applicants submit Letters of Inquiry (LOI)[1] and, occasionally, the Foundation issues requests for proposals. Among funding priorities, the Foundation supports initiatives to raise public awareness about the disease and advocate for funding, as well as to research for new and innovative tools and to make better use of existing methods. LOI for the global health programme (including TB) are reviewed on a continuous basis throughout the year.
- The Foundation has opened a small office in China to run its programmes supporting the Ministry of Health, which includes a TB component (US$33 million for five years).

The Global Fund

- The Global Fund to Fight AIDS, Tuberculosis and Malaria provides grants to support interventions for the prevention, treatment, care and support of persons infected and directly affected by HIV/AIDS, TB and malaria. These are developed at country level.
- In response to the call for proposals in ongoing funding rounds for the Global Fund, CCMs[2] prepare proposals and submit them for review and approval for funding. CCMs are organised with the participation of public and private organisations involved in fighting the three diseases in the affected countries, and/or other entities.
- Proposals are submitted to the Secretariat to the Global Fund according to the guidelines for proposals as published and regularly adapted by the Global Fund.
- Recommendations for Round 10 onwards:

  - Universal access to high quality TB control measures.
  - Better targeted TB proposals which will increase success rate.
  - Increased emphasis on TB/HIV collaborative activities.
  - Increased demonstration of cost-effectiveness of TB prevalence surveys in proposals as recommended by TRP in Round 9.
  - Repackaging TB messages to make it more positive and increase the focus on achievements and success stories.
  - Urgent need to scale-up MDR treatment.
  - Inclusion of infection control measures.
  - Better demonstration of HSS support in TB proposals.[3]

Stop TB Partnership

- The Stop TB Partnership's Challenge Facility for Civil Society provides grants on an annual round basis (between US$5,000 and 20,000) to community-based CSOs whose work focuses on advocacy and social mobilisation activities in countries affected by TB.
- It aims to make the voices of vulnerable communities affected by TB heard by local policy-makers. Proposals are selected by an independent selection committee composed of a maximum of eight representatives from the community affected by TB; NGOs from developing and developed countries; NTP managers and multilateral or technical agencies.
- Applications are submitted directly to the Stop TB Partnership Secretariat.

Photo courtesy of WHO/TBP/Davenport

�’ Photo: **A biologist prepares TB cultures at Daniel Carrion Hospital, Peru.**
The expanded capacity to diagnose TB/MDR-TB is a global priority for TB control.

USAID

- The US Agency for International Development (USAID) is an independent agency that provides economic, development and humanitarian assistance around the world in support of the foreign policy goals of the United States.
- Non-profit organisations based outside the United States contact the USAID mission at country-level.
- USAID's TB programme consists of five components, all in accordance with the STOP TB Strategy:

  - DOTS expansion and enhancement
  - Scaling up management of MDR-TB and XDR-TB
  - Addressing TB/HIV co-infection
  - Strengthening health systems and human resource capacity.
  - Developing new tools and improved approaches.

- USAID supports partnerships that empower people with TB and communities, including ACSM.
- USAID supports advocacy for implementation of the Patients' Charter for TB care to enable patients and communities to raise awareness about the rights of people with TB and to strengthen patient provider relationships.

➘ **Links to the websites of the main international funders can be found in Resources Section 7.**

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End notes

1. LOI is document submitted by an institution seeking a grant or funding for a project. The LOI describes the purpose of the project, summarises the project's goals, and includes financial information for the project.

2. CCM prepares proposal based on local needs and financing gaps. As part of the proposal, the CCM nominates one or a few Principal Recipients (PR). In many cases, development partners assist in the preparation of proposal.

3. Atun, Rifat, Presentation: "The Global Fund support for TB control", STOP TB Symposium, Cancun, Dec. 2009.

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Section **8**

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WHO Ministerial meeting in Berlin in 2007

This meeting aimed to:
- Ensure the support of the Member States for the monitoring and follow-up of the Berlin Declaration on Tuberculosis, adopted at the WHO European Ministerial Forum on Tuberculosis in Berlin on 22 October 2007
- Ensure proper visibility on the fight against TB at a policy level
- Present European plans to fight TB
- Increase awareness of high policy administrators in European countries on TB control and elimination.

The TB Europe Coalition is an informal group of European CSOs that, since 2008, has initiated action to raise the profile of global TB within EU institutions. It agreed this meeting would be a good opportunity to:

- Network with policy-makers and other stakeholders across Europe (particularly from East European countries)
- Get CSO visibility
- Help advance lobbying with MEPs to include TB in the European Union (EU) agenda and EC budgetary process.

A CSO statement was prepared and circulated at the meeting to help disseminate its advocacy messages. It urged Ministers of the European Region to raise the standards of care and response to fight TB at national level. It called for special efforts to address MDR/XDR-TB and better integrate TB and HIV/AIDS interventions.

Referring to the recent World Health Assembly Resolution 62.15 on MDR-TB, the statement further called for "countries to develop country indicators and to support monitoring and evaluation of the implementation of the measures outlined in this resolution".

It also asked EU donor countries to support the development of and ensure access to new and more effective tools – drugs, diagnostics and vaccines – for TB control and meet the pledges made in Berlin vis-à-vis sustainable financing by supporting global and regional plans to stop TB 2006–2015.

Finally, the statement reiterated the offer of partnership from civil society to the Ministers of the European Region, presented at the WHO Ministerial meeting in Berlin in 2007. It included specific asks to strengthen CSO engagement in national responses.

Immediate outcomes

The key messages of the CSO statement were echoed in the presentations of different participants during the meeting, including Louise Baker from the Stop TB Partnership.

As a result, there was clear reference to CSOs' requests for:
- the establishment of a mechanism or platform for civil society, NGOs and professional groups' involvement in TB control across the region (similar to the inter-service group on HIV/AIDS, coordinated by EC-SANCO)
- the review of GFATM eligibility criteria for middle-income countries; and
- the EC to explore alternative support to MDR-TB high-burden countries within the WHO/EURO region likely to lose eligibility for GFATM funds.

Civil Society Organizations Statement

At the Meeting on Tuberculosis under the High Patronage of H.R.H the Grand Duchess of Luxembourg, Organized by the European Commission, WHO EURO and European Centre for Disease Prevention and Control (ECDC)

June 30th – July 1st 2009.

Members of European Civil Society Organizations attending the Meeting on Tuberculosis issue this statement calling for the urgent attention of States of the EU Region to call to the facts that:

- **Although TB mortality rates have decreased or remained stable over recent years**, TB - a curable disease - kills nearly two million people per year worldwide, with around 65000 deaths per year in the WHO European Region, so 7 deaths every hour.
- **Despite the decline of TB incidence in the EU, in 2007, a total of 431 518 new cases were registered** in the 53 countries of the WHO European Region. Specifically, in the EU and EEA/EFTA countries substantial increases were observed in Malta and Iceland, and Ireland, Greece, United Kingdom and Sweden saw an increase in new cases.
- **Multi Drug Resistant and extensively drug resistant TB (M/XDR-TB) is on the rise and receiving inadequate or inappropriate responses**. It is alarming that in 2007 within the WHO European region, **some 10% (43,600 cases) of the new TB cases and 43% of re-treated cases were estimated to be MDR-TB cases and 42 300 HIV co-infections were estimated among the new TB cases**. Out of the 27 member states considered with high MDR TB burden, 15 are from Europe and 5 are from EU.
- **Meaningful civil society participation in policy and program development and implementation remains weak**. The contributions and perspectives of civil society in TB prevention and control remains relatively absent in policy and programmes, advocacy and decision making processes.
- **Financial resources and commitments for the TB global response remain insufficient**. The most recent data available on resources allocated to TB programmes ($3 billion in 2009) and research ($483 million in 2007) are insufficient compared to the $5 billion needed for programs in 2009 and the $2 billion for research in 2007. At these funding levels the targets set by The Global Plan to Stop TB (2006-2015) will not be realized by 2015. EU countries and national governments must invest in new diagnostics, vaccines and treatments.

In light of the current state of affairs, we urge Ministers of the European Region to:
- **Raise the standards of care and response to fight TB at national level**. Provide technical assistance to Ministries of Health and CSO engaged in fighting TB at national level, in order to help them restructure their health system to ensure that they can adequately respond to the epidemic by providing comprehensive care and support.
- **Re-emergence of the disease fuelled by the HIV epidemic and the development of MDR TB require renewed efforts** in both control programmes and activities to ensure early diagnoses, availability of appropriate therapy, and completion of treatments. Referring to the recent World Health Assembly Resolution 62.15, we call for "countries to develop country indicators and to support monitoring and evaluation of the implementation of the measures outlined in this resolution".
- **Special efforts to better integrate TB and HIV/AIDS control plans and implementation programs is needed**.

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- **Support the development of and ensure access to new and more effective tools for TB control**, including diagnostic tools that can be used at the point-of-care, treatment regimens that are proven to be effective in children and compatible with HIV medications and new vaccines that will protect against all forms of TB and will be safe for people with HIV.
- National TB programmes to clearly outline the r**ole of civil society in TB control efforts in national plans**. National TB programmes to partner with civil society organizations to actively find TB cases among vulnerable communities.
- Make community based treatment and support, including for MDR TB, and active TB case finding key components of an effective TB response, in order to ensure that all TB patients, including **the most marginalized groups, e.g. migrants and drug users, are able to receive treatment that respects their human rights and ensures treatment success, according to the principles outlined in** *The Patients' Charter for Tuberculosis Care*.
- **Meet the commitments made in Berlin in 2007 vis-à-vis securing sustainable financing by supporting the Global and Regional Plans to Stop TB 2006-2015** and addressing the funding gap between the total resources available and the resources needed to control TB.

We reiterate the offer of partnership from Civil Society to the Ministers of the European Region, presented on 22nd October 2007, at the WHO Ministerial Forum. Now that two years have passed, we strongly urge the European Commission to support civil society involvement in TB national response and strategy by:

- **Urgently creating a European Think Tank co-ordinated by DG SANCO**, with the mandate to relate to TB in the EU and neighbouring countries: exchanging information and contributing to a coordinated approach to combat TB, focusing on the European Union and the neighbouring countries; to facilitate informal consultation between the Commission, the Member States, the Candidate Countries and the EEA Countries.
- This should include **funding and promoting a civil society platform within the WHO Europe region** to facilitate stronger collaboration among civil society organisations, recognising their essential role as partners in national and regional TB control programmes. This process should be initiated as soon as possible, with the aim of a functioning platform by the end of 2009.
- Ensuring that countries within the European region are not adversely affected by the next Global Fund eligibility criteria review. The European Commission and European states should develop together a strategy to **safeguard and sustain successful programs that protect the most vulnerable groups** in European high burden countries and encourages meaningful civil society participation.

↘ **Source: Eurosurveillance**

Resources / Section 2

Useful links

↘ The Revised Global Plan to Stop TB: www.stoptb.org/global/plan

↘ MDR-TB: www.who.int/tb/challenges/mdr/en

↘ Links with HIV/AIDS: www.advocacypartnership.org/userfiles/files/TB%20and%20HIV-AIDS.pdf

↘ New TB diagnostic test: www.who.int/tb/features_archive/new_rapid_test/en

↘ TB and stigma: www.aidsalliance.org/includes/Publication/TB_and_Stigma_May09.pdf

UK Coalition to Stop TB: TB/HIV Working Group Action Plan 2010

Appendix C: TB/HIV and MDR-TB Working Group Action Plan 2010

Members of the Group:

1. (Vacant possible) International AIDS Alliance
2. Alison Grant, London School of Hygiene and Tropical Medicine
3. Denise O'Sullivan, London School of Hygiene and Tropical Medicine
4. Gerri McHugh, Society of Tropical Medicine and Hygiene
5. José Julio Divino, Ely Lilly
6. Louise Holly, RESULTS UK
7. Luciana Brondi, London School of Hygiene and Tropical Medicine
8. Keith Alcorn, NAM
9. Nikki Jeffery, Target TB
10. Pamela Hepple, Médecins Sans Frontières
11. Philipp du Cros, Médecins Sans Frontières
12. Renato Pinto, TB Alert
13. Toby Capstick, UK Clinical Pharmacy Association

Overall Goal:

The TB/HIV and Working Group is aimed at influencing the HIV/AIDS community based in the UK and globally to integrate TB more systematically and effectively into their HIV/AIDS interventions (e.g. in terms of programme and advocacy work).

Objectives:

1. Increase awareness about HIV/TB co-infection issues among civil society organisations, decision-makers, health professionals and community groups, through gathering and dissemination of relevant information and encouraging dialogue among policy-makers, NGOs and other stakeholders.
2. Build the capacity of UK-based HIV/AIDS and health-oriented organisations to address TB/HIV and MDR-TB, in terms of programming and advocacy work.
3. Increase collaboration among TB, HIV/AIDS and health-oriented organisations around HIV/TB issues.

↘ Photo: **Members of the UK parliamentary delegation meet with Indian MPs during a visit to TB programmes in India. Together they sign the Call to Stop TB.**

Photo courtesy of RESULTS UK

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Objective	Description of activities	Responsible party	Timeframe	Resources needed	Means of verification
1. Raise awareness about HIV/TB co-infection issues in the UK and abroad: identify the needs of UK-based HIV/AIDS and health organizations in terms of TB/HIV co-infection issues (knowledge, programme development within a broader Health Systems Strengthening themes	1.1 Mapping of UK-based HIV/AIDS and health-related organizations working or not on TB/HIV co-infection, main policies, guidelines and best practices on (through electronic search, liaising with BAS on ongoing audit, Stop TB, etc.)	Renato to update the document	March 2010	No costs. Working time	Mapping of TB/HIV material report done. All to utilize the documents for Policy and lobbying activities
	1.2 Develop calendar of events in the UK and abroad addressing TB/HIV co-infection issues	Belinda	8th Feb 2010	No costs. Working time	Calendar developed upload an updated version 2010
	1.3 Distribute copies of global and national policy and guidelines mapping to UK Coalition members and relevant organizations.	Renato/Aparna/Keith	Ongoing work	No costs. Working time.	Mapping developed and distributed. Upload on coalition website
	1.4 All working group members to ensure that TB is adequately integrated into AIDS Consortium working groups	TB/HIV working members to join different AIDS Consortium WGs	First quarter of 2010	Membership staff time	As many as possible TB/HIV working group members to join different consortium working groups
	1.5 Ensure TB information is incorporated in HIV information, education and communication materials vice versa; by regular update through AIDS Consortium working groups	By TB/HIV WG			
	1.6 Support campaign working group to disseminate TB/HIV & messages to decision-makers and public through media and Campaign strategy	All members + media and campaign group members	On-going	No costs. Working time	Reflection of TB/HIV issues through Campaign strategy

Objective	Description of activities	Responsible party	Timeframe	Resources needed	Means of verification
2. Build the capacity of HIV/AIDS and health-oriented organizations on TB/HIV and MDR-TB	2.1 TB/HIV working group to organize a follow up meeting with AIDS consortium to strategize on best ways to utilize HIV/TB workshop recommendations	Belinda to organize	Feb/March 2010	No cost associated, staff time	Hold a meeting and reach a joint agreement on joint collaboration on TB/HIV within AIDS Consortium
	2.2 Help develop guidelines on TB/HIV collaborative activities for joint applications to the GFTAM	Optional, each Individual organizations to decide on how to proceed with this	As appropriate	No cost associated	Individual organisation to update WG on any developments during WG meetings
3. Increase collaboration among TB, HIV/AIDS and health-oriented organizations around HIV/TB issues.	3.1 Organise joint activities for World AIDS Day 2010: TB/HIV identified as key theme	All members + media group	ongoing work	Organizational budget	TB/HIV materials featured in WAD events and publication
	3.2 Joint APPG AIDS and TB meeting around World AIDS day 2010	APPG TB Coordinator		Organizational budget	Joint event with APPG AIDS and TB
	3.3 Participate in UK Consortium on AIDS and Stop AIDS campaign activities	All members	Pre-Post Election	No cost	

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Clarifications on CCM Minimum Requirements, 2005

↘ www.theglobalfund.org/documents/ccm/Clarifications_CCM_Requirements_en.pdf

Differentiating various types of advocacy by their immediate audiences

Type	Immediate Audience	Tactics	Champions	Examples
Indirect				
Research advocacy	Opinion leaders	Politically relevant research Budget & policy analysis Opinion polls	Jeffrey Sachs	Commission on Macroeconomics of Health Global Plan to Stop TB
Coalition advocacy	Multipliers (i.e. bringing new partners or networks into the coalition)	Conventions & partner forums Web-based dissemination Newsletters Sign-on letters		Global Health Council Stop TB Partnership Roll Back Malaria Partnership
Mass advocacy	Sustainers (fundamentally changing social opinions and priorities on an issue)	Internet activism Petitions Mass events Celebrities Electoral processes Cause-related marketing Popular media	Bono Youssou N'Dour Chaka Chaka Rahman	ONE Campaign Make Poverty History
Direct				
Bureaucratic advocacy	Policy enablers	Communiqués Declarations & pledges Targets	Mario Raviglionie Jorge Sampaio Stephen Lewis	United Nations General Assembly Special Session on HIV/AIDS World Health Assembly
Protest advocacy	Political protesters	Marches and demonstrations Boycotts Civil disobedience	Zackie Achmat	ACT-UP TAC
Legal advocacy	Courts	Class action suits & litigation		
Policy advocacy	Decision-makers	Parliamentary/Congressional delegations Editorial board meetings Committee hearings Direct correspondence (e.g. phone calls, letters, etc.) Individual meetings	Winstone Zulu Lucy Chesire Bono Members of Parliament/Congress	ACTION Bread for the World Friends of the Global Fight

Taken from Best Practices for Advocacy. ACTION Project 2007.

↘ http://c1280432.cdn.cloudfiles.rackspacecloud.com/ACTION-Best-Practices-Guide.pdf

Resources / **Section 5**

Skill 1: Creating parliamentary champions

Links to documents produced by the APPG on Global TB

↘ 'APPG on Global TB annual report'.
www.appg-tb.org.uk/documents/APPG_Annual_Report.pdf

↘ 'Turning UK TB Policy into Action: the view from the frontline'.
www.appg-tb.org.uk/documents/RCN_APPG_BTS_report_final.pdf

↘ 'Scaling up the UK's response to the Global TB Epidemic: An Agenda for Action'.
www.appg-tb.org.uk/documents/agendaforaction.pdf

Skill 4: Speaking powerfully

Links to media clips

↘ **Media clip 1:** Marlon Brand, Martin Luther King, Harvey Milk, Ronald Regan.
www.advocacypartnership.org/userfiles/files/speaking_powerfully_media_clip_1.asf

↘ **Media clip 2:** Helen Diane Foster, Barak Obama, Stephen Lewis.
www.advocacypartnership.org/userfiles/files/speaking_powerfully_media_clip_2.asf

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Skill 9: Preparing a press release

Sample Press Release

Mary Robinson, Archbishop Desmond Tutu, and Professor Muhammad Yunus Call on Leaders of G8 Countries

WASHINGTON, DC (June 30, 2009) — In an open letter sent today to the leaders of all G8 countries, Desmond M. Tutu, Archbishop Emeritus of Cape Town; Mary Robinson, former president of Ireland; and Professor Muhammad Yunus, founder of Grameen Bank, called on G8 heads of state to renew their commitment to the world's children. The authors of the letter specifically asked the leaders to announce an agreement on the creation of a Global Fund for Education (GFE) at the G8 Summit, which will be held July 8–10 in L'Aquila, Italy.

The letter acknowledges the world's financial climate, but notes that world leaders must "provide the safety net of knowledge to the world's poorest children and save them from paying with their lives for our financial mistakes. Education must be an integral part of the global response to the economic crisis."

Worldwide, 75 million children are unable to attend school, 226 million adolescents are not enrolled in secondary school, and 770 million adults remain illiterate. In over 50 countries, many in sub-Saharan Africa, half of all children never complete primary school. Yet literacy is widely considered a prerequisite for economic development, and education the key to breaking inter-generational cycles of poverty. Despite this, global aid for basic education has been decreasing at an alarming rate.

The authors of the letter stressed the importance of U.S. leadership on this issue, citing President Barack Obama's campaign pledge to make $2 billion available for the launch of the GFE. "Such a bold and ambitious plan should be endorsed by other members of the G8 through a public commitment to such an initiative, which must be launched before the end of the year with full funding," the letter said.

Additional Resources:
↘ Global Fund for Education Backgrounder
   www.globalaidsalliance.org/page/-/PDFs/GCE_Global_Fund_Education.pdf
↘ Civil Society letter to President-elect Obama
   www.globalaidsalliance.org/page/-/PDFs/Education_for_All_CSO_Sign_On_Letter.pdf

Skill 10: Writing for the media

Sample OpEd

Old enemy, new challenge: The re-emergence of tuberculosis could reverse a decade of advances in the fight against HIV/Aids

Guardian newspaper, United Kingdom
Monday 9 June 2008 18.30 BST
By **Lucy Chesire**

No one should die from tuberculosis. It can be cured. Yet throughout Africa, TB is the leading killer of people living with HIV.

In the past 10 years, the global community has made tremendous progress in scaling up treatment programmes for

those living with HIV in communities and towns once regarded as too remote to support distribution of antiretroviral drugs.

Yet today that progress is being threatened. An old enemy – tuberculosis – has re-emerged with a vengeance that could reverse a decade of advances in the fight against HIV/Aids.

Across the globe, the deadly combination of HIV and TB – long thought of in Europe as a disease of the past – is fuelling a TB resurgence globally. There are 14 million people co-infected with TB-HIV in the world. In my own country, Kenya, TB is by far the greatest killer of people infected with HIV. Fifty percent of TB patients there are HIV positive.

Because of their compromised immune systems, people like me, living with HIV, are more likely to get TB, more susceptible to active infection and more likely to die unless we receive proper treatment. I spent seven months in a Kenyan hospital battling tuberculosis as it spread from my chest to my lymph nodes to my knees. Only with invasive surgery, antiretroviral therapy and pure chance did I become one of the lucky ones.

This week in New York, the UN general assembly's special session on HIV/Aids is bringing together world leaders and civil society to strengthen action on HIV/Aids.

But without a joint strategy to help the millions of people worldwide living with both TB and HIV receive the treatment and care they need, this cannot succeed.

Every TB patient needs to be screened for HIV, every person living with Aids needs to be tested for TB and there needs to be joint planning between national TB and HIV programmes.
And a strategy will do nothing to help the sick and the dying without strong commitments from rich governments to fund new approaches to TB/HIV co-infection. Furthermore it will not help those at risk unless we invest in new tools for TB prevention.

TB never really disappeared - it was just confined to the poor, the sick, the ignored. But over the last 15 years, the number of new TB cases has more than doubled in countries with the highest rates of HIV infection. The World Health Organisation estimates that globally, one-third of people living with HIV are also infected with TB.

In Kenya, activists and politicians have called for a declaration of a national disaster to confront the twin epidemics. In many African countries, the emergence of multi-drug resistant TB and extensively drug-resistant TB (XDR-TB) has brought a new urgency to treatment, as doctors grapple to save lives without adequate solutions. Reports of an XDR-TB case in Glasgow earlier this year raised the alarm in the United Kingdom – a wake-up call for all of us to think about TB.

The situation will continue to deteriorate unless we have new tools to fight TB. Though now widely available, the drugs we have were invented 40 years ago, must be taken daily for at least six months and, if compliance is not perfect, can continue to breed drug resistance.

The one existing TB vaccine was invented 85 years ago and offers only some protection against a small percentage of severe childhood cases. The frustrating truth is that we cannot accurately diagnose TB. The most commonly used TB diagnostic tool detects only half of new cases and cannot identify drug-resistant disease strains. In HIV-positive patients, it is even less accurate, detecting only 20% of TB infections.

We must maintain efforts to prevent and treat HIV. But we must also transform TB prevention,

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diagnostics and treatment with new TB vaccines, new TB tests and new TB medicines. Researchers around the world are committed to this task.

Their success will require sustained support from donor governments. The UK has long been a leader in responding to the global TB epidemic. But much more is needed.

For too long TB has been ignored, simply because it targets the weak – whether those with HIV or the old, young or poor. Through vision, action, new technologies and increased funding, we must prove once and for all that what is good for the world's most vulnerable citizens is, in fact, good for us all.

guardian.co.uk © Guardian News and Media Limited 2010

Sample Letters to the Editor

The World Bank's shameful record
The Guardian, Tuesday 5 May, 2009

The recent report on the World Bank's health investments should be a cause for alarm - especially its shockingly poor performance in the Africa region (World Bank admits most health aid fails, 1 May). In this time of economic crisis, it is crucial that money is spent effectively. The evaluation of the World Bank shows that it has been championing approaches which have often failed to ensure accountability and results. Efforts at health sector reform were among the worst performing. By contrast, 89% of infectious disease programmes targeting diseases such as tuberculosis and malaria were deemed successful but received minimal funding.

With the deadline for the Millennium Development Goals approaching fast, we must ensure that efforts to improve the health of the world's poorest people are not going to waste.
Louise Holly
Deputy Director, Results UK

The Independent Evaluation Group has scrutinised the work of the World Bank in delivering healthcare for the poor over a decade, finding that in Africa 73% of the bank's health, nutrition and population projects failed.

Despite this abysmal performance, the UK government has recently awarded the bank an additional £2bn over three years. And yet, in contrast, the Global Fund to Fight Aids, TB and Malaria, which last month reported that it has saved an estimated 3.5 million lives, is facing a funding shortfall of between £2.7bn and £6.7bn over the next two years. In terms of accountability in Africa, 69% of Global Fund programmes performed at the highest ratings. Where grants were not performing, they have been stopped and reformed.

We are calling on the UK government to increase its funding to the Global Fund by £183.45m for 2009 and 2010 - paying its fair share according to donor income levels. If the World Bank wants to continue in health then it must demonstrate that it is able to commit to delivering results for the poor.

Malaria Consortium
The Stop Aids Campaign
UK Coalition to Stop TB
World Vision UK

Make TB history
The Guardian, Wednesday 24 March 2010

The World Health Organisation reports record levels of multidrug-resistant tuberculosis (Report, 19 March). We urge the UK government to take concerted action now. TB is a major killer, yet it is not being treated as a major priority. Not only is there a rise in TB cases globally, it is on the increase in the UK, with some of the highest rates in western Europe. Today, on World TB Day, the UK Coalition to Stop TB launches a new campaign TB: A disease of the past? Action now. Tuberculosis is not a disease of the past. It should be.

Aaron Oxley Results UK, **Julie Morgan MP** Co-chair, all-party parliamentary group on TB,
Dr Amina Jindani World Without Tuberculosis, **Mike Mandelbaum** TB Alert, **Nikki Jeffrey** Target TB

Urgent action needed to tackle TB
From The Times, March 23, 2009
Challenges ahead: tuberculosis is the single biggest killer of HIV patients worldwide

Sir, Remarks by the Pope (report, Mar 17) that condoms could make the global HIV epidemic worse reflect an attitude that will only serve to hinder progress made to combat this ruthless disease. However, there are greater challenges to HIV/Aids programmes than religious dogma. Tuberculosis is the single biggest killer of HIV patients worldwide, and in sub-Saharan Africa HIV has caused TB incidence to triple since the 1990s. Without proper treatment, it is estimated that 90 per cent of people living with HIV die within months of developing TB.

Data to be released by the World Health Organisation today, World TB Day, are expected to report levels of TB-HIV co-infection significantly higher than originally estimated. Evidence shows that prevention and care for patients are far more effective when TB-HIV services are combined, but sadly insufficient money and resources have been dedicated to developing integrated services. It is critical that this is scaled up as soon as possible; a failure to respond will result in thousands more preventable deaths each year. This, of course, will depend on the response of international donors in the face of the global financial crisis. Despite recent pledges from the US and renewed commitment from the UK, the Global Fund to Fight Aids, TB and Malaria and the Global Plan to Stop TB are still facing serious shortfalls in funding. Through the programmes they support, these institutions have made a real impact on the fight against communicable disease. A drop in funding threatens to halt or even reverse progress made.

With TB-HIV co-infection rates rising rapidly, as well as cases of drug-resistant TB emerging in many countries (including the UK), world leaders attending the forthcoming G20 meeting need to fulfil urgently the promises they have made to avoid potentially devastating effects.

Mike Mandelbaum, Chief Executive, TB Alert
Louise Holly, Deputy Director, Results UK
Sheila Davie, Advocacy Partnership
Paul Thorn, Project Director, the Tuberculosis Survival Project
Nikki Jeffrey, Director, Target Tuberculosis
Gerri Mchugh, Chief Executive, Royal Society of Tropical Medicine and Hygiene
Lara Brehmer, Comdis (Communicable Disease Research Programme Consortium)
Lynn Young, Royal College of Nurses
Toby Capstick, Lead Respiratory Pharmacist, St James University Hospital
Evelyn Harvey, Health Development Networks
Dr Luciana Brondi and Ruth Mcnerney, The London School of Hygiene and Tropical Medicine

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Challenges in advocacy M&E

- Causal relationships: The complexity of issues handled by activists makes it difficult to determine cause and effect between NGO advocacy initiatives and outcomes[1] that is, how to attribute a specific change in the law or in more general attitudes and values in society to the advocacy/lobbying efforts of a single NGO or coalition? The influence of external factors is also unpredictable – i.e. the political situation, disasters or opposition tactics may influence outcomes more than anything within the advocate's control.

- Compromise versus outright victory: Absolute victory, in the sense of achieving all the sought-after objectives, is rare – often compromise is necessary, with some objectives being jettisoned or modified. This introduces an element of subjectivity in determining whether gains were significant, or whether small gains were consistent with the wider objectives of the campaign. There are likely to be a variety of opinions among different partners and stakeholders in a campaign. Indeed advocacy may bring together organisations that are not all trying to achieve the same thing.

- A moving target: the objectives of advocacy are moving targets sensitive to external factors. They will change as the environment changes through unrelated factors, as progress is made or when resistance and setbacks are encountered. Thus indicators[2] of success may also need to change: an indicator that was relevant at the start of the campaign may become irrelevant as the campaign widens or changes its focus.

- Advocacy can mean many things and is increasingly collective: Advocacy includes a whole range of tactics such as influencing, lobbying, campaigning, demonstrations, boycotts, etc. Different organisations work in different ways and advocacy increasingly takes place through networks and coalitions. Indeed, positive results may often reflect the sum of a variety of approaches. It may be difficult to assess which approach makes the difference; even harder to isolate the impact of a particular organisation. Claiming or measuring individual attribution may be counterproductive and harm cooperation. It may be more important to improve how organisations are working together for a common purpose.

- Long-term policy work: Furthermore, much advocacy and policy work is long term. This poses a challenge in measuring impact as opposed to outcomes. Measuring policy change may not be sensitive enough to changes in the short term. It is also important to measure implementation of the policy, not only its formulation.

- A conflictive process: Advocacy can be a conflictive process. Engaging in advocacy work can have political consequences in terms of groups' relationships with others.

To learn from experience: advocacy work is often unique to a country (e.g. political, social and cultural) context, rarely repeated or replicated, so that the gradual accumulation of knowledge by repetition does not happen. Reflection on advocacy work is even more important to ensure that lessons are learned throughout the process. Deciding what succeeded or failed is often a case of looking at which mix of strategies worked in a given situation or comparing how different strategies influenced a particular target audience or contributed to the achievement of advocacy efforts. Learning is more effectively built by:
↘ reflecting regularly on whether expected outcomes have been achieved;
↘ collecting anecdotal or other evidence for documentation;

Monitoring the external situation in order to recognise and record other factors that may have influenced achievement or not of results. Often it is more useful to focus on why plans need to be changed than to spend time collecting data on pre-determined indicators.

End notes

1. Outcome is the impact or result expected to achieve from outputs (that are the activities undertaken, such as meetings, workshops, production of policy briefs, press conferences etc.). Inputs are the resources used to undertake activities in terms of staff and production costs.
2. Indicators are the evidence to be collected that shows the outcomes have been achieved.

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Major indicators (Stop TB and Global Fund)

The WHO Stop TB Department developed a Stop TB Planning Matrix and Framework in order to guide TB proposal development according to the six objectives and 20 sub-components, also called Service Delivery Areas (SDAs) of the Stop TB Strategy.

The matrix lists all Stop TB Strategy objectives, SDAs, and provides a menu of main activities and corresponding indicators. This tool corresponds with the Global Fund M&E and reporting tools.

Please find below indicators related to advocacy only (as opposed to ACSM as a whole), that may help you develop indicators to your advocacy work.

Stop TB Planning Matrix and Framework

Stop TB strategy objective	SDAs	Menu of activities	Programmatic indicators	Data source
Objective 1: Pursue High Quality DOTS Expansion and Enhancement	SDA 1.1 Political commitment with increased and sustained financing	Advocacy component of ACSM Place TB high on the political agenda Foster political will Increase and sustain financial and other resources	Number and/or percentage of funds budgeted by the government for TB control out of the total national health budget	National budget and financial reports Media coverage
Objective 5: Empower People With TB and communities	SDA 5.1 ACSM Advocacy, communication and social mobilization and Patients' Charter for TB Care	5.1.1 General management 5.1.2 Advocacy 5.1.3 Communication 5.1.4 Social mobilization 5.1.5 Patients' charter (e.g. training health care staff and technical assistance) **Additional Advocacy activities** Meeting with policy and decision-makers Raise the profile of TB issues addressed by advocacy campaign in Media Write policy briefs and political statements/manifestos	Population with correct knowledge about TB: mode of transmission, symptoms, treatment and curability (%) People in selected community expressing accepting attitudes towards people with TB (%) Number of meetings with policy and decision-makers held Number of articles addressing advocacy campaign issues Number of documents produced and disseminated	Knowledge, attitude and practice (KAP) study, case studies and focus group discussions Reports and minutes on the meetings Newspapers., case studies Reports to donors

Note: The above are not really exclusive indicators for advocacy but ACSM.
However please note that the Stop TB Matrix refers menu of activities SDA 5.1 for the advocacy component of ACSM.

Case Study: Basanti's story on the TB election asks

Basanti's Story

Basanti Munda is an 18-year-old girl from Jharkhand State, India, where she lives with her mother, father and younger brother and sister. TB is a big public health problem in her village. Basanti's aunt also died from TB. Basanti had symptoms for more than a year before she was finally diagnosed. Basanti initially visited a traditional healer which is common practice in her village. The family paid the equivalent of about £4 for this. When this did not work, her parents took her to private doctors locally but she was still not properly diagnosed.

Finally when Basanti was extremely sick and unable to walk, her parents hired a car and travelled to a private hospital in the adjoining State of Orissa, where hospital facilities are better. She was given an ultra sound and tuberculin skin test and diagnosed with extra-pulmonary TB of the ovaries.

This cost the family the equivalent of over £100 in fees, for which they had to take out loans. Eventually, Basanti was linked to the local health centre so that she could receive free TB treatment through the government health service and her TB treatment be closely monitored by a local health worker.

Source: TB Election Asks, UK Coalition to Stop TB, March 2010 at www.stoptbuk.org

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Links to main international funders

↘ DFID: www.dfid.gov.uk

↘ Bill and Melinda Gates Foundation: www.gatesfoundation.org

↘ The Global Fund: www.theglobalfund.org

↘ The Stop TB Partnership: www.stoptb.org

↘ USAID: www.usaid.gov

Additional resources

Organisations and websites

Organisations	Websites
ACTION	www.action.org
The Global Fund to Fight AIDS, TB and Malaria	www.theglobalfund.org
Panos	www.panos.org
RESULTS UK	www.results.org.uk
RESULTS USA	www.results.org
Stop TB Partnership	www.stoptb.org
Treatment Action Group (TAG)	www.treatmentactiongroup.org
UK Coalition to Stop TB	www.stoptbuk.org
UNDP	www.undp.org
UNICEF	www.unicef.org
World Health Organization/Stop TB Department	www.who.int/tb
World Health Organization Euro	www.euro.who.int
World Bank	www.worldbank.org

Glossary

Abbreviation	Definition
ACSM	advocacy, communication and social mobilisation
APPG	all party parliamentary group
ARV	antiretroviral
AIDS	acquired immunodeficiency syndrome
BCG	Bacillus Calmette-Guérin – a vaccine against tuberculosis
CBO	community based organisation
CCM	country coordinating mechanism
CSO	civil society organisation
DFID	Department of International Development
DOT	directly observed treatment
DOTS	the basic package that underpins the Stop TB Strategy
GDF	Global Drug Facility
GFATM	Global Fund to Fight AIDS, TB and Malaria
GLC	Green Light Committee
HBC	high-burden country
HIV	human immunodeficiency virus
HSS	health system strengthening
IMF	International Monetary Fund
IPT	isoniazid preventive therapy
ISTC	International Standards for Tuberculosis Care
LOI	letter of interest
MDR-TB	multi-drug resistant tuberculosis
NGO	non-governmental organisation
PAL	Practical Approach to Lung Health
PLHIV	people living with HIV
PPM	public-private mix
SCSO	southern civil society organisation
TB	tuberculosis
TRP	Technical Review Panel (of the Global Fund)
WB	World Bank
XDR-TB	extensively drug-resistant TB

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