ADVOCACY, COMMUNICATION AND SOCIAL MOBILIZATION FOR TB CONTROL

Collection of country-level good practices






Stop TB Partnership

World Health Organization

WHO Library Cataloguing-in-Publication Data

Advocacy, communication and social mobilization for TB control: collection of country-level good practices.

1.Tuberculosis - prevention and control. 2.Behavior therapy. 3.Patient advocacy. 4.Consumer participation. 5.Strategic planning. 6.Case reports. I.World Health Organization.

ISBN 978 92 4 150062 3 (NLM classification: WF 200)

Printed in Italy

Layout: blossoming.it

Acknowledgements

This document contains good practice examples of country-level Advocacy, Communication and Social Mobilization (ACSM) submitted by the following organizations and entities: Project PACS (Programa de Agentes Comunitários de Saúde) (Brazil), National TB Control Programme (NTP) and Programme d'Appui au Monde Associatif et Communautaire (PAMAC) (Burkina Faso), PATH (Cambodia), Profamilia (Dominican Republic), Foundation Alli Causai (Ecuador), Ghana Stop TB Partnership (Ghana), Operation ASHA (India), Family Health International (Malawi), Project Concern International (Mexico), Centre for Health Policies and Studies (Moldova), Provincial Health Office, Malolos, Bulacan Province (Philippines), Catholic Relief Services - United States Catholic Conference of Bishops (Philippines), HealthRight International (Romania), National TB Control Programme (Sudan), Project HOPE (Tajikistan), PATH (Ukraine).

Alka Dev (independent TB consultant) was responsible for writing the first few drafts of the document, compiling all the submissions and re-writing them to ensure consistency of language and structure. Richard Pinkham (communications consultant) continued the work of Alka, and was responsible for the finalization of the document. Young-Ae Chu (Stop TB Partnership) and Elisabetta Minelli (Stop TB Partnership) coordinated the production of this document with oversight and guidance provided by Netty Kamp (KNCV Tuberculosis Foundation).

The following Advocacy, Communication and Social Mobilization (ACSM) Core Group members (of the ACSM Sub Group under the DOTS Expansion Working Group) reviewed the document and provided feedback in the development of this publication: Chibuike Amaechi (The Good Neighbour Inc.), Elisa Canqui Mollo (United Nations Permanent Forum on Indigenous Issues), Young-Ae Chu (Stop TB Partnership), Colleen Daniels (World Health Organization), Alka Dev (independent TB consultant), Mao Tan Eang (National Center for TB and Leprosy Control, Cambodia), Héctor Oswaldo Jave Castillo (National TB Programme, Peru), Netty Kamp (KNCV Tuberculosis Foundation), Elena McEwan (Catholic Relief Services), Hara Mihalea (PATH), Austin Arinze Obiefuna (Afro Global Alliance), Ogechi Onuoha (Journalists Against AIDS Nigeria), Lana Velebit (World Health Organization), Monica Yesudian (World Health Organization).

Special thanks to Susan Bacheller (United States Agency for International Development), Charlotte Colvin (PATH), Netty Kamp (KNCV Tuberculosis Foundation), Elena McEwan (Catholic Relief Services), and Ogechi Onuoha (Journalists Against AIDS Nigeria) for their thorough review and valuable input into the various drafts of this document.

The Stop TB Partnership appreciates the contribution of USAID which made the development of this publication possible.

"The people have the right
and duty to participate
individually and collectively
in the planning and implementation
of their health care".

Declaration of Alma-Ata, 1978

"Now I know much more about TB,
its causes, its symptoms: coughing,
night sweats, weight loss;
the need to take the medication
as prescribed and without interruption,
that the person affected does
not need to be isolated,
that TB is curable, and, most importantly,
that TB does not mean death."

Juan Hernandez, Person Affected by TB, 40 years old, Mexico (through interpreter)

Acronyms

ACSM	–	Advocacy, communication and social mobilisation
CBO	–	Community-based organisation
CMS	–	Community mobilisation specialist
DOT	–	Directly-observed therapy
DOTS	–	The basic package that underpins the Stop TB Strategy
FHI	–	Family Health International
GP	–	General Practitioner
IEC	–	Information, education & communication
KAP	–	Knowledge, Attitudes & Practices
MDR	–	Multidrug-resistant
NTP	–	National TB Programme
PAC	–	Public Awareness Campaign
PATB	–	Persons with TB or Affected by TB
PHE	–	Peer Health Educators
PLWHA	–	People living with HIV/AIDS
PPM	–	Public-private mix
PSA	–	Public-service announcement
TB	–	Tuberculosis

Preface

This document has been born out of the need for practical examples of the fifth component of the Stop TB Strategy: "Empower people with TB, and communities through partnership".

Since the conception of the Advocacy, Communication and Social Mobilization (ACSM) Subgroup, and the incorporation of community involvement and ACSM in the Stop TB Strategy, many useful documents have been produced to guide countries in the implementation of these relatively new concepts in TB control.

Several countries are showing good practices in ACSM leading to improvements in early detection, better adherence to treatment, reduction in stigma and discrimination. These good results have been achieved in a variety of settings such as in countries with high prevalence of MDR TB, TB/HIV co-infection or other related problems increasing vulnerability to TB, like extreme poverty in slum areas or among ethnic minorities. As a response to the need from countries for practical examples to be adopted or adapted in their own settings, the ACSM Subgroup, with constant support of the Stop TB Partnership Secretariat, selected this collection of Good Practices.

At the moment of publishing this document many countries have developed their ACSM strategies and projects. I hope this document contributes to the further expansion of ACSM practices, focused on the specific problems each country is facing. There is no magic bullet or blue print model of ACSM that suits all countries, but this collection can be of use in giving guidance to ACSM planning, implementation, monitoring and evaluation in countries.

The document is meant to be a first edition in a series of good practices to follow, building this way, gradually, more appropriate, successful, and diverse as well as evidence-based experiences of ACSM and community involvement in TB control in many countries around the world.

I wish you a pleasant reading!

October 2010
Dr Netty Kamp
Senior TB adviser KNCV TB Foundation
Chair ACSM Subgroup Stop TB Partnership

1 Introduction

Purpose of the document

The purpose of this document is to highlight cases in which Advocacy, Communication and Social Mobilization (ACSM) interventions have contributed to a positive outcome of tuberculosis (TB) control activities directed to a range of audiences and settings. It is intended for on-the-ground stakeholders who are interested in successfully integrating ACSM strategies and activities into TB control programming, as well as for decision-makers who can provide greater political and financial support for ACSM activities at the national, sub-national and international level.

ACSM is a relatively new technical component within the Stop TB Strategy, but its application is increasing quickly. In recent years, many partners and countries have adopted ACSM models – notably including the engagement of communities and patients in TB care and prevention – with the purpose of expanding the reach of TB programmes in innovative and effective ways.

A significant differentiator of ACSM strategies is their focus on patient and community empowerment. This element promotes the integration of community-based programming into the otherwise medical and vertical health service delivery model that has traditionally been employed by TB control programmes.

The community approach also opens the door for greater involvement in the effort by partners with different skill sets, an addition that greatly enhances the ability of TB programmes to extend prevention, diagnosis and treatment services into hard-to-reach communities. It also facilitates useful and cost-effective integration with other public health efforts, such as nutrition, maternal and child health and HIV/AIDS programmes.

The cases in this document illustrate some of the innovative ways in which projects have incorporated ACSM strategies in their TB prevention and treatment efforts. Although the nature of the activities they have employed varies, each of the projects is an example of how to put the fifth component of the *Stop TB Strategy* – *"Empowering people with TB and communities through partnership"* in practice.

A partnership with communities affected by TB is at the core of each project. It is a critical tool for augmenting the efficacy of the overall TB control activities, especially as regards such vital goals as:

- improving the rate of early case detection and treatment adherence,
- combating stigma and discrimination against TB patients,
- creating an enabling environment to empower people affected by the disease, and
- mobilizing political commitment and resources to address TB.

By sharing good practices, other implementing partners will hopefully be able to learn from, replicate and enhance the activities detailed in these pages.

We wish that on-the-ground stakeholders who are currently implementing ACSM activities or are interested in developing this component for their TB programmes will manage to take something new from these practices. These cases should serve to stimulate new ACSM interventions elsewhere that satisfy the local contexts and desired outcomes, whether they are greater treatment adherence, an enhanced national commitment to arresting the spread of TB or significant advances in the ways communities and health officials care for those affected by the disease.

Methodology

The ACSM Subgroup (ACSM SG), currently under the DOTS Expansion Working Group of the Stop TB Partnership, was established in 2005. Its mandate is to foster the development and implementation of more strategic and effective ACSM by promoting country-level partnering initiatives and innovative approaches for TB prevention and control. Previous publications produced by the group have included documents aimed at disseminating knowledge, attitudes and practices (KAP) guidelines and guiding principles for inviting communities in the fight against TB.

ACSM SG selected the 16 ACSM cases included in this document because they represent a range of effective partnerships and interventions instituted in different locations and under different epidemiological conditions. These good practices share the common principles of engaging TB patients and affected communities, and building linkages between communities, programmes and health systems. The cases also exhibit innovative approaches to increasing DOTS coverage, case detection and treatment success rates, and to reducing the stigma related to TB. Partners implementing in areas of high HIV prevalence often furthered the model by targeting both TB and HIV epidemics.

Process of Selection

In order to collect a representative sample of good practices, the ACSM core group circulated a call for submissions that instructed contributors to describe the TB situation in their implementation area, the population served, discuss their ACSM objectives and activities and present results. In response, 35 implementers submitted case studies. The ACSM Core Group found that 16 submissions exhibited a clear case of good practice, explained the case's key steps and documented the results achieved.

This document presents those 16 final case studies, which come from a total of 15 countries (two case studies were accepted from the Philippines), representing all WHO regions. All selected submissions clearly stated their project's specific challenges in arresting the spread of TB, and explained how an ACSM-inclusive solution enabled an effective response to the situation. Almost all of the cases presented a quantitative representation of the results the intervention achieved in reducing the community's TB burden. This requirement meant that numerous promising good practices were not selected for inclusion, either because they were in the early stages of implementation or did not sufficiently exhibit clear evidence of success.

Disclaimer

The data and information contained in this document are being presented as were provided by each organization that submitted a good practice. WHO and the Stop TB Partnership makes no representations or warranties, either expressed or implied, as to their accuracy, completeness or fitness for a particular purpose. Neither do we accept any responsibility or liability with regards to the reliance on, or use of, such data and information.

2 Key Lessons Learned and Recommendations

I Enhancing DOTS Services

1.1 Patient-centred approach: adapting health services to the needs of the patient

Numerous cases noted that when health services were made more accessible – such as by making DOTS centres more geographically convenient to the target user base and/or by expanding centre hours – the results included noticeably higher early detection and treatment adherence rates. In addition to permitting greater cooperation from the patients, these modifications helped make the patient flow more efficient (leading to a more effective diagnostic process), and also allowed for the tailoring of daily treatment practices according to the specific needs of patients and their families. This lesson, which holds particularly true in the case of drug and alcohol abusers and homeless or unemployed people, also enables people with day jobs to access TB services before or after work.

The case study from India presents a programme that builds on this principle by establishing DOTS centres directly in slums, greatly enhancing their accessibility for patients. The Brazil case also showed how the creation of a DOTS centre in the slums, as well as home visits by health workers living in the same neighbourhood, can considerably improve adherence.

1.2 Improving quality of interpersonal communication at the health-service level

Improving the communication skills of health providers (both those covering TB and those with a general mandate) proved to make a dramatic difference in at least three cases (Romania, Tajikistan and Ukraine). In each of them, the implementers found that approaching patients as partners, offering psychosocial support where needed and using a more personalized participatory approach to TB education all helped to significantly reduce treatment interruption, as the patients developed feelings of trust with the providers.

1.3 Increasing access to diagnostic services by facilitating sputum sample transport from community health centres

In settings where TB diagnostic services are located far from the community (such as in rural or sprawling urban areas), or where Primary Health Care (PHC) units do not perform smear microscopy, it was found that enabling sputum transport from (specially trained) community-based health centres

to diagnostic facilities can reduce diagnostic delays and speed the confirmation of symptomatic status. The studies from Brazil, Malawi and the Philippines (Maguindanao province) provide good examples of how such an intervention can contribute to improved case detection.

II Empowering patients and communities

Creating patients' clubs can provide peer support for those affected and their family members throughout the treatment process. Putting the focus on the patient also creates opportunities for tailored participatory health education or counselling sessions, with the content dictated by the TB sufferers' specific needs.

Long-term patients' associations can further work to reinforce patients'-rights-based approach to TB service delivery. This approach, which entails both the patient and provider recognizing their rights and duties, can catalyse significant improvement in treatment adherence rates. And empowered patients, working in collaboration with their local TB programmes, have proved adept at effectively advocating for better access to quality DOTS.

In the cases of the Dominican Republic, the Philippines (Maguindanao) and Mexico, patients' clubs and associations served both as support structures for community-based ACSM efforts to increase early detection and treatment adherence, and also as a means of sustaining patient advocacy work beyond the life of the project. The value of recognizing the patient experience is further exemplified in the TB Photovoice project (documented in the Mexico case study), which provides intimate portraits of TB patients and their families. Such initiatives can be a powerful tool for education and advocacy.

III Partnering with affected communities and civil society organizations

Establishing local "fight TB networks" with communities, the private sector and local institutions can help meet the needs of patients, while also raising TB awareness amongst the general population. Furthermore, such efforts can play an important role in reducing the stigma associated with the disease.

In the case of both Brazil and the Philippines (Bulacan province), multi-sector community networks served as important agents in the campaign to improve social support and treatment incentives for TB patients and, ultimately, in targeting TB-related stigma. The Ghana study further exemplified the positive impacts that are made possible by engaging local opinion leaders.

Community health workers and volunteers are also essential to the implementation of any community-based intervention. This lesson was buttressed by the cases of the Dominican Republic, the Philippines (Bulacan province) and Romania. In Brazil, Ecuador and India the identification of TB suspects and delivery of treatment was directly and effectively managed by community members under extremely difficult conditions, including geographic isolation and urban slum settings. Community volunteers also played vital roles in cases in Ghana, Malawi, the Philippines and in Tajikistan. The main activities of these groups included education, identification of symptoms, referral, defaulter tracing and, at times, DOTS provision.

Cooperation with local nongovernmental organizations (NGOs) and community-based organizations (CBOs) are among the most effective vehicles for forging useful partnerships with the affected communities. These groups' abilities and local knowledge and contacts are often vital tools in the effort to reach stigmatized and vulnerable groups and to successfully advocate with health officials for better TB patient treatment.

The local organization's smaller scale and local origins can also help to find innovative solutions to problems unique to the settings in which it operates. It often possesses intangible attributes that larger, overseas-based organizations do not have, including flexibility, adaptability to local conditions, high levels of staff motivation, and at times, an ability to reach the contacts needed to secure local resources.

In the cases of Brazil, India and Romania, the direct involvement of CBOs in providing community-based TB care reduced diagnostic delays and improved treatment success. In Burkina Faso and the Dominican Republic, the coalition of NGOs supporting people living with HIV/AIDS (PLWHAs) showed an increase in the detection of TB suspects and a significant rise in adherence where HIV patient supporters were involved.

IV Improving supportive communication methodologies

The first step in achieving empowerment is increasing stakeholder knowledge and awareness of the important aspects of TB control. All ACSM good practices highlight the need for appropriate communication strategies and materials specially designed or adapted to suit the specific problems, target groups and stakeholders. The case study from Ukraine shows how this approach is necessary, not only for patients and community members, but also for health providers, whose attitudes and communication skills can have a significant impact on reducing treatment default rates.

V Measuring the results

Being able to present a quantitative representation of an intervention's beneficial impacts is critical for the projects' success and the further expansion of ACSM activities. Anecdotal data alone is not enough to support the continuation or scaling up of ACSM activities within TB programmes; donors and NTP programme managers require evidence that the activities are making a difference in case detection and treatment outcomes. However, ACSM is largely a qualitative process, which makes measurement a challenge. The ACSM/TB experience suggests that implementers should consider the following factors when attempting to gauge the success of their ACSM efforts.

5.I Link ACSM interventions to specific gaps in reaching case detection and treatment outcome targets and identify appropriate indicators for which anticipated improvements are expected.

ACSM activities are not "stand alone" activities and should be linked to identified gaps in case detection and treatment outcome targets. Programmes do not support communication campaigns only for the sake of improving knowledge among vulnerable populations; rather, the improved knowledge is expected to yield measurable changes in case detection indicators, such as the number of TB suspects presenting themselves at DOTS centres for further evaluation of symptoms. Thus, it is critical to fully incorporate monitoring and evaluation into ACSM planning processes so that data collection needs, data sources and reporting methodologies are clearly articulated.

For instance, a pre-intervention survey in Cambodia indicated that citizens of Phnom Penh are considerably more likely to seek health care from private providers than from the government medical apparatus. Using this information, the project engaged, *inter alia,* private pharmacies, which play a uniquely powerful role in the national health care arena. By recruiting them to play a referral role, the number of new cases identified was increased significantly.

Similarly, an assessment in Romania observed that an at-risk disadvantaged group – the Roma – were unable to gain access to diagnostic services because of stigma against them and because of bureaucratic obstacles to treatment seeking. By working within the system to change these situations, the project was able to identify and treat a significant number of smear-positive cases that otherwise would have gone undiagnosed.

For optimal measurement of impact, if ACSM is expected to result in measurable increases in early case detection (for example, by reducing the time period between the emergence of TB symptoms and the arrival of the TB suspect at a health clinic), then a special data collection effort beyond routine reporting may be necessary. This activity should be planned and budgeted accordingly.

Often, multiple types of data will be needed to accurately illustrate the impact of ACSM. Some examples include a catalogue of what resources were devoted to ACSM, programme data on the actual implementation of the activities, a list of the ones that took place and their immediate outputs (e.g. the number of people trained), their direct results, as well as related changes in case detection and treatment outcomes.

5.2 Ensure that proper baseline data on key indicators targeted by the intervention is collected before implementation begins

In most cases, implementers were able to carry out baseline knowledge, attitude and practice (KAP) surveys and focus group discussions to document TB information needs and related ideas and behaviours. However, in some cases, baseline KAPs were not followed up with end-line surveys, making it difficult to definitively credit changes to the specific interventions. This shortcoming illustrates why it is essential, when implementing a baseline survey, to budget and plan for an end-line survey with the same population, to definitively measure the impact of the intervention on KAP.

It is also critical to ensure there is a clear data-analysis and data-use plan, so that all stakeholders understand how the KAP survey results are used to plan ACSM activities and what changes in KAP and key outcome indicators can be expected as a result of implementing ACSM.

It is also important to remember that changes in KAP alone are not usually enough to convince donors and policy-makers that ACSM activities are worthy of their investment; KAP surveys measure understanding of TB issues and intended or reported behaviour, not actual outcomes. Therefore, KAP survey data should be supplemented with data from the routine information system (e.g. the number of TB suspects and smear-positive cases reported on a quarterly basis), so that improvements in KAP are directly linked to key national tuberculosis programme (NTP) indicators. These should be collected at baseline and end-line and presented along with KAP and other programme and process data on the interventions themselves. The coordinated presentation of this data will play a vital role in making a compelling case to donors and NTPs for the initiation or expansion of ACSM activities.

5.3 Understand the challenges inherent in measuring outcomes and institute plans to overcome them

There are numerous reasons why obtaining quantitative measurements of the projects' success is difficult. When the projects either have a short time-span or are ongoing, conducting baseline and end-line surveys can seem overly expensive to donors. Also, due to the lag in reporting TB cohort data, it has been a challenge for most case studies to establish a causal link between the good practice and overall TB outcomes. In some cases, organizations were able to report on locally collected outcome data, but these still need to be reviewed and validated by the country's National TB Control Programme.

Finally, when ACSM approaches are implemented in conjunction with other ongoing TB programme improvement activities, it is difficult to isolate and assess its impact. Attention should be paid to designing a monitoring-and-evaluation plan as part of the overall project plan, with a planned supervision component. Detailed implementation data, along with an assessment of other interventions taking place in the same timeframe, can help ACSM activity managers – in common with the managers of the other TB programme components – to clarify the role that ACSM has played in improving outcomes.

5.4 Establish metrics to measure impacts of media outreach programmes

Although several partners held workshops for journalists, the results and outcomes of engaging the media were generally not measured or reported. In one case, the number of publications was recorded but the circulation of the media sources was not.

Similarly, radio and television broadcasts were sometimes carried out, but with no assessment of their reach. More attention needs to be dedicated to documenting these outcomes if media-outreach activities are to be included as a good practice.

3 Case Studies of Good Practices
























BARANGAY TB PATROL
BUWAN NG







Brazil

Reaching the unreached

community participation in TB prevention and care in a Rio de Janeiro slum

Submitted by: Project PACS
(Programa de Agentes Comunitários de Saúde)

About Project PACS

The PACS project began as a community based DOTS project in 2003, as a partnership between the TB programme of Rio de Janeiro, John Hopkins University/USAID, the local Catholic Church and the Rocinha favela (slum) community. The Catholic Church provided physical space in their local facilities to house a health team consisting of 2 nurses and 40 community health agents or Agentes Comunitarios de Saude (ACS). ACSs are legally recognised as a component of a nationwide community health programme that was introduced in 1994.


Agente
Comunitário
de Saúde

TB Control challenge:

With a 2007 rate of TB incidence reported at 93.7 per 100 000, Rio de Janeiro's rate is almost twice as high as the national estimate. Default rate is at around 13%. Although Rio's incidence has slowly decreased in the last five years (109.9 in 2003), TB continues to thrive in the city's slums (or *favelas*), overcrowded areas with very little proper infrastructure and public services. Like many of Rio's *favelas*, Rocinha is a densely packed, unplanned hillside community. It is notifying approximately 300 TB cases per year since 2000.

Rocinha is served by a single primary care health centre, which has a high patient load and only operates during the weekdays. Before the project started, all TB suspects were usually sent to this small health facility for first medical consultation. Further TB diagnostic and treatment services – such as sputum check and medical diagnosis – require referral to a facility outside of Rocinha. In 2003, Rocinha's treatment success rate was 70%, with a defaulter rate as high as 20%.

ACSM Intervention:

The project implemented intensive training and engagement of community health agents to both work directly in the community to provide TB services, and to build social support networks for patients and families.

Project PACS established a health team focused on the selection and training of 40 ACS, all of whom are residents of Rocinha, and some of whom were former patients. Each of the agents passed a basic test on health knowledge, followed by an intensive one-month training course that covered general aspects of the role of an ACS, the importance of home visits, as well as key information on TB prevention and control.

Following the training, the team of ACSs conducted a mapping exercise of all the homes and families in Rocinha, visiting all houses, for the determination of such health risk factors as the level of access to clean water and sanitation services. The exercise also enabled the identification of the most vulnerable socioeconomic groups (e.g. those suffering from extreme poverty, unemployment or from drug and alcohol abuse) and the identification of TB suspects and patients.The neighbourhood was divided into 15 zones, with two or three ACSs living and working in each zone.

The next step was to set up a Social Support Network, mapping all the local civil society organizations, schools, community leaders and commercial enterprises that could provide any type of support to the population. Employment officers were also contacted in order to secure work for unemployed patients. The ACSs visited these possible network partners, explaining their project and establishing partnerships for eventual support for TB patients and their families. This has resulted in a new sense of community commitment toward patient support, manifested in the introduction of such services as transport to the TB dispensary and the donation of food baskets.

The ACSs provided a comprehensive package of community DOTS under the leadership of the two nurses. Their main tasks included:

- collection and storage of sputum samples (diagnostic and follow-up), safe transport to the lab located outside Rocinha and feedback of results to patients;
- contact tracing within households and peer communities (e.g. friends, work, bar, school, etc.),
- prophylaxis for contacts < 5 years old and HIV positive;
- follow-up with patients to ensure that they go to their monthly medical check at the TB dispensary outside Rocinha, with arrangement of transport, if needed;
- provision of directly-observed therapy (DOT) at the homes of patients who cannot come to receive daily DOT at the health centre;
- updating patient treatment cards and
- additional care as needed (e.g. food, treatment for side effects, socioemotional support, with special efforts made in the case of patients suffering from alcohol and drug problems) to ensure treatment adherence.

The nurses maintain the registers and forward data to the municipality. The ACSs also undertake a wide range of health education activities in the neighbourhood, such as visiting day-care centres, schools, churches and community organizations.

In addition to distributing informational pamphlets and promotional materials, they perform puppet theatre and participatory Information, Education and Communication (IEC) and coordinate health campaigns in collaboration with local radio and television stations, which provided free airtime.

TB Control challenge:

With a 2007 rate of TB incidence reported at 93.7 per 100 000, Rio de Janeiro's rate is almost twice as high as the national estimate. Although Rio's incidence has slowly decreased in the last five years, TB continues to thrive in the city's slums (or favelas), overcrowded areas with very little proper infrastructure and public services. Like many of Rio's favelas, Rocinha is a densely packed, unplanned hillside community. It also features a rate of incidence of over 500 cases per 100 000 habitants, having notified approximately 300 TB cases per year since 2000.

Rocinha is served by a single primary care health centre, which has a high patient load and only operates during the weekdays. Before the project started, all TB suspects were usually sent to this small health facility for first medical consultation. Further TB diagnostic and treatment services – such as sputum check and medical diagnosis – require referral to a facility outside of Rocinha. In 2003, Rocinha's treatment success rate was 70%, with a defaulter rate as high as 20%.

Project Results:

The impact of the project is directly measurable through the treatment success rate which rose from 70% in 2003 to 86% in 2007, and the project has achieved an extremely low defaulter rate (3.9%).

Treatment outcomes under treatment of PACS Rocinha, 2004-2007

Year	Number of cases	% Successfully treated	% Defaulters
2004	313	90	4.4
2005	265	88	6.3
2006	266	80	7
2007	301	86	3.9

Lessons:

The project offers several lessons for future ACSM efforts, some of which are applicable to the Brazilian context and others with more universal relevance. By using agents who are from the communities in which they are working, an extremely high degree of trust is created. This has resulted, among other positive outcomes, in potential patients approaching the ACSs for guidance, a situation that greatly aids early detection and subsequent care.

Another enabler of success has been the guidance on rights and responsibilities the ACSs offer each patient and family. The project has provided the agents significant familiarity with the nation's extensive – but typically under-utilized – social support policies for impoverished, unemployed and/or disabled Brazilians. This instruction has resulted in favela patients receiving considerably enhanced financial support when they start their treatment, a major factor in the low defaulter rate and higher quality of life.

Burkina Faso

Civil society mobilization
to improve TB case detection and treatment outcomes among vulnerable populations

Submitted by: National TB Control Programme (NTP) and Programme d'Appui au Monde Associatif et Communautaire (PAMAC)

About NTP and PAMAC

The National TB Programme of Burkina Faso launched its DOTS programme in 1995 and has achieved 100% national coverage. Diagnostic and treatment services are free of charge for TB patients. The NTP aims to pursue a process of decentralization of TB diagnosis and treatment.

PAMAC was formed in 2003 to bring a community-based approach to reducing the impact of HIV/AIDS in the country. On the strength of its success in enabling a community prevention and care programme for HIV/AIDS, the group was mandated to develop and implement the community aspect of Burkina's National Tuberculosis Control Programme financed by the Global Fund Round 4.

TB Challenge:

A major obstacle to reducing the burden of TB in Burkina Faso is the low level of health services utilization demonstrated by most of the population, a condition that hinders the identification of more suspects and results in diagnostic delay.

The three main barriers to higher public health service utilization are: a preference for traditional healers and self-medication over initial health centre visits; a lack of transport and money to adhere to regular follow-up during treatment; and the poor attitude of health care staff toward TB patients.

ACSM Intervention:

Mobilization of civil society and community organizations to conduct an integrated programme of community education and community-based case management to achieve improved case detection and treatment completion.

Building on its experience with HIV/AIDS and in partnership with the NTP, PAMAC sought to expand the reach of the TB programme to address specific barriers to TB care-seeking by focusing on vulnerable populations, such as the most affected urban poor, nomads and PLWHA.

The programme's initial step was to identify local organizations that had several years of implementation experience, as well as the management and technical assistance capacity needed to oversee the efforts of smaller, less experienced community associations. Ultimately, 11 local organizations were selected to both implement activities directly and to support the efforts of nearly 300 associations to reach the most vulnerable populations.

The NTP and PAMAC also promoted the participation of traditional healers, home-care providers and community leaders, seeking to utilize their links in the community to encourage referral of suspects and to promote better awareness of TB within their networks.

The project conducted training sessions on technical aspects of TB for the community associations and focal organizations, the latter being trained separately on management skills, support or supervision and monitoring and evaluation (M&E). Other training topics included Information Education and Behaviour Change Communication (IEC/BCC), effective techniques for collaborating with health-care workers in the delivery of community-based TB services, financial planning and monitoring and reporting.

Once trained, the participating associations – with the support of 18 diagnostic and treatment centres – were able to implement BCC activities. One of the most important interventions was a series of TB sensitization activities that, while applicable to the entire population, was particularly targeted at such vulnerable populations as PLHIV, nomads and urban slum dwellers.

All communication activities were coordinated through the NTP's newly formed Communications Department, which designed culturally appropriate communication messages and promoted such community-level patient support initiatives as household visits, psychosocial support contact and defaulter tracing.

Other project outputs included the introduction of a functional referral system, which helped to send TB suspects to diagnostic centres for sputum testing, an M&E system that uses electronic recording and reporting, as well as regular meetings at different levels between members of public health services and civil society partners (PAMAC and local organizations).

Project results:

In the October 2005 - June 2008 period, the project recruited nearly 300 local organizations across the nation (including 15 that represented former TB patients), and trained more than 3500 community actors, including: local organization project managers, BCC educators, traditional healers, home care providers, health-care workers and community association members.

The network's BCC activities reached approximately 1 150 000 people, and identified or sputum checked 6670 TB suspects, of which 580 (8.7%) tested positive for TB. Furthermore, participating organizations provided 4184 TB patients with treatment and psychosocial support such as home visits and provision of meals. Contact tracing was also implemented through community case-management, with 170 contacts agreeing to be tested and 77 (45%) testing smear positive.

Lessons:

Evidence has demonstrated that the contributions of communities to case detection can yield impressive results where contagious smear-positive cases are concerned. Involving communities in contact tracing as part of community-based case management can also produce a high yield of new smear-positive cases.

Other notable factors in the programme's ability to effectively reach so many people were: the community associations' ability to adapt their materials and communication strategies for each particular target group; the use of a partner approach to engage relevant stakeholders and effective coordination between government and civil society groups.

Cambodia

Engaging private sector players to enhance early detection rate efforts

Submitted by: PATH Cambodia

About PATH Cambodia

PATH works to create sustainable, culturally relevant solutions that enable communities to break longstanding cycles of poor health. PATH has been active in Cambodia since 1996 and working to stop TB in the country since 2005. From 2005-2009, PATH worked to introduce a public-private mix (PPM) solution to slowing TB's spread in the country. With USAID funding and collaborative support from the National Tuberculosis Programme, the Phnom Penh Municipal Health Department, the provincial health departments and the Pharmacists Association of Cambodia, PATH piloted the PPM programme in two operational districts of Phnom Penh. The project has since been rolled out to cover 11 of Cambodia's 24 provinces.


HALF THE CASES HALF THE
USAID
PATH
STOP POVERTY

TB Control challenge:

Cambodia is among the countries most affected by tuberculosis, with the WHO ranking it 21st among the 22 high TB burden countries. Approximately two-thirds of all Cambodians are infected with Mycobacterium tuberculosis and around 13 000 people die from TB disease annually. Cambodia's TB incidence rates show 226 cases per 100 000 habitants for new smear-positive pulmonary TB and 506 per 100 000 for all forms of TB and a TB mortality rate of 87 per 100 000.

The nation's high rate of incidence is exacerbated by a low national level of TB knowledge and the large distances between most places of residence and the nearest health facilities. Another significant compounding factor is the prevailing patient belief that public health workers treat them with disdain and charge them high costs for treatment, both of which further contribute to poor care-seeking behaviour.

ACSM Intervention:

The project identified the inclusion of private pharmacies as a significant platform from which to increase the early TB detection rate. A 2004 survey of TB suspects in capital city Phnom Penh showed that, for 75% of respondents, the private sector is the first choice of care provider, as opposed to the country's public health facilities. The costs involved in seeing a private health care provider means that the pharmacist is frequently the first – and often only – point of health care contact for most Cambodians.

Given this overwhelming preference (which appears to be growing – a similar survey in 2002 found that only 60% of respondents looked first to private health care providers), the Ministry of Health approved a pilot project in which PATH and its partner groups would work to increase linkages between public health care actors and the pharmacy sector.

The project aimed at mobilizing community pharmacies – which for the above reason serve an unusually important role in Cambodia's health care sector – to get directly involved in the identification and referral process of clients with signs and symptoms of TB. It is necessary to note that a key element in the feasibility of this process was the willingness of the pharmacy owners to take part in the referral process without expecting any payment. Indeed, their conscientious participation potentially results in lost revenues. This sense of charity owes to them being community-minded and also, to an extent, from the Buddhist belief in "making merit" or doing good deeds to achieve good karma.

With this predisposition to help on a voluntary basis already in place, the project's main objective was to effectively marshal their enthusiasm to assist in the process. This entailed increasing the pharmacy owners' and their staff members' TB assessment skills and enhancing the mechanisms that enable them to effectively refer people with signs and symptoms of TB to DOTS health centres and referral hospitals. The project also worked to increase the ACSM capacities of the National TB Programme staff at all levels enabling them to design, implement, and monitor site specific ACSM plans.

The project implementers achieved these goals through an intensive programme of creating ACSM-related materials, designing and implementing advocacy campaigns, developing training curricula for pharmacy staff, training pharmacy and cabinet staff in how to identify TB suspects and refer them to the appropriate public facility. The materials included a Basic Facts on TB kit to be given to people displaying TB symptoms, comprised of an easy-to-read booklet describing what actions the person suspected of TB should take, as well as a number-stamped referral sheet he/she should present to the DOTS facility.

Another goal was to strengthen both the public and private sectors in TB case management. In the public sector this was achieved through various ACSM interventions that provided the health staff at all levels with better understanding of their clients and their needs, and strengthened their communication skills resulting in improved client-provider interactions and client satisfaction. The Cough-to-Cure Pathway model was used to help the health staff to identify barriers at all stages of the continuum of care where their clients have greater opportunity to drop out and develop appropriate interventions. This further resulted in the increased numbers of referrals reported reaching the DOTS services.

Significant time and effort was spent ensuring that all providers understood the importance of using standardised reporting forms. This step was critical for accurately quantifying the impacts of the project.

Project Results:

The outreach efforts of the project resulted in the ultimate recruitment of 1573 private providers, 520 DOTS health centres and 38 referral hospitals. All private providers have signed memoranda of understanding with the Ministry of Health and the provincial health departments and are actively participating in the referral of TB suspects whom they encounter.

Furthermore, all pharmacists, pharmacy - and cabinet staff were trained in proper techniques of TB assessments and referrals, more than 700 health centre staff received training in TB-related communications, and 169 health-centre-based outreach educators were trained to improve the way they communicate with people affected with TB.

The impact of the project is seen in the number of TB suspect referrals that have been made by private providers (mostly pharmacies) in the project network This figure, which stood at 14 TB cases (all forms) in the 2004-2005 period, grew to 839 TB cases (all forms) by 2009.

Lessons:

The project owes its success to several factors, notably including the high level of buy-in evinced by government. Without the support of the public sector in engaging its private sector counterparts, the project would have foundered. It was vital that the government should uphold its responsibility to report on activities to ensure that non-follow-up levels were kept low, and that communications with the private sector partners were constant and productive.

Securing the commitment of the private sector was also a vital precursor to success. Without sustainable action on the part of the pharmacies and cabinets, the project would have generated underwhelming results. In the end, the only reward expected from the project was recognition of the role the pharmacists play. (This recognition came in the form of a certificate presented to each high-achieving participant by the Minister of Health.)

Sustainability was also enabled by the inclusion of the Pharmacy Association of Cambodia, which helped to mobilize its members and which will continue to play an organizing role at the conclusion of the formal project.

Dominican Republic

Improved TB case detection through NGO coalition building to implement community-based education and case-finding activities

Submitted by: Profamilia

About Profamilia

Profamilia is a Dominican NGO with more than 43 years experience conducting successful reproductive health programmes, particularly among vulnerable groups such as migrants, Haitian-Dominicans and those living in extremely poor urban slums and rural areas. The NGO has been selected by the Country Coordinating Mechanism (CCM) to serve as the Principal Recipient for GFATM TB projects (Rounds 3 and 7) and to assume responsibility for monitoring the activities of sub-recipient organizations. Profamilia is contributing to TB control in the country by applying strategies learned through its decades of experience in community-based health programming and by collaborating with local NGOs that have experience in HIV/AIDS prevention and care activities.


PROGRAMA CONTROL DE LA TUBERCULOSIS
DPS LA VEGA
CIGARRILO, ALCOHOL, DROGAS;
CONDUCEN A TUBERCULOSIS
LA TUBERCULOSIS

TB control challenge:

The Dominican Republic has one of the highest rates of TB incidence in Latin America, with 69 cases per 100 000 (2009 WHO Report). Country conditions that favour the emergence and spread of TB are: poverty, migration, alcohol and drug abuse, high rate of TB/HIV infection as well as a widespread lack of knowledge of basic information regarding TB. Stigma and discrimination are also present in the general population, as well as among health personnel. All of these factors contribute to the currently prevalent situations of low or late case detection and poor treatment outcomes.

ACSM Intervention:

Build strategic partnerships within a coalition of local HIV/AIDS-focused NGOs to implement community-based activities to raise TB comprehension and foster proactive anti-TB efforts at the grassroots level.

Profamilia developed a formal coalition of 16 NGOs and CBOs that already had significant experience in the HIV/AIDS area, training them in general aspects of TB, identification of suspects and principles of DOT and working with them to develop and implement social mobilization activities in 18 of the country's 30 provinces. Covering a population of more than 400 000 people, the project sought to increase case detection rates, to improve access to treatment and treatment adherence and to decrease the stigma associated with TB and the discrimination against affected people.

Once they were trained, the coalition organizations in turn trained community health workers (or health promoters) in general aspects of TB, identification of suspects and principles of DOT support to enable them to carry out health education and behaviour-change projects and TB patient care. The groups also supplemented promoters' activities by helping to provide rights-based health advocacy services at the local level, to secure enhanced nutritional support, flexible clinic schedules and more patient-friendly services. They also assisted with the development and distribution of high-quality education materials based on the results of previous formative research efforts.

The activities of promoters have been supported through advocacy meetings with local politicians and businessmen to create a more supportive environment for TB patients. Patients and ex-patients themselves created the Dominican Association of Patients Affected by TB in order to defend their human rights, improve social conditions and reduce the stigma associated with TB and TB/HIV and to end the discrimination against sufferers. These activities have helped people suffering from TB symptoms to come forward earlier to seek diagnosis and treatment.

Project results:

In the period 2006-2008, the coalition trained over 2400 promoters who distributed Information, Education and Communciation (IEC) materials via a variety of channels, including home and workplace visits, health education sessions at schools, clubs and churches and neighbourhood board meetings. Health education materials were designed for separate target groups; for example, Creole-language materials for Haitian migrants and adapted leaflets for prison populations. As a result, approximately 200 000 Dominicans were effectively educated about TB.

The project's advocacy efforts also attained significant results, including greater resource allocation from local government units. Some examples of this are the provision of school breakfast for TB patients and the transport of sputum samples to testing facilities.

Promoters have assisted with case finding by seeking out TB suspects during their IEC activities. In the above-mentioned period, 2838 were referred to health centres for TB testing, of whom, 2715 were tested and 164 (6% of this figure) were diagnosed as smear-positive for TB. An additional 440 contacts were also referred for testing.

Lessons:

The Dominican case illustrates how local organizations with community mobilization capacity – even those with limited TB experience – can be harnessed to effectively and sustainably identify suspects and promote early detection efforts at the community level. The scope of their work can be increased in remote areas, where they have exhibited the capacity to provide badly needed treatment support to patients. Furthermore, the case shows how the advocacy power created by a coalition of NGOs and CBOs can be effective in promoting improved care and enhanced access to local and national resources.

Ecuador

Using community DOTS in a remote indigenous community to achieve high detection and treatment success rates

Submitted by: Foundation Alli Causai

About Foundation Alli Causai

The Foundation Alli Causai (FAC) has been working in Ecuador's remote rural areas with the indigenous Kichwa group for more than 25 years. FAC has coordinated community organization activities aimed at improving sanitary and health conditions, enhancing access to clean water and basic nutritional requirements, augmenting food production, preventing and treating prevalent diseases and providing public management and political advocacy services. FAC has been providing TB services in these communities for the past 10 years.


Programa de Alfabetización y Educación "YO, SI PUEDO"

TB Control Challenge:

The communities of *El Corazón, Cicalpa, Facundo Vela and Simiatug* in Ecuador are largely rural, the majority being poor agricultural people belonging to the *Kichwa* ethnicity. For the most part, they have little or no access to health services, due to geographical, economic and cultural factors. Community members typically seek care with traditional healers or at basic rural health units that offer only a small package of primary health care services.

ACSM Solution:

To engage the entire *Kichwa* community – through their local farmer or peasant organizations and village health workers – in active case finding and treatment support. The ACSM solution was designed to help meet the local needs for earlier and more effective detection of TB and improved treatment outcomes in areas where coverage of public health services is deficient.

Local community organizations approached the Foundation Alli Causai (FAC) to offer technical support to programmes that would improve their health situations. These community organizations, which are FAC's principal partners, have a long history of development focused on improving living conditions and on advocating to ensure that their communities' basic human health rights are met.

Activities undertaken by FAC are often related to community development, education and health, but they also aim to strengthen overall political leadership in communities, and – supported by local leaders – identify and train village workers to deliver health services, among other public services.

In the period 2006-2008 – as a result of a previous participatory community health assessment in which chronic cough was identified as one of the most frequently occurring health problems – FAC offered to support the communities in activities focused on TB case detection and treatment.

Awareness-raising was achieved through meetings with community assemblies headed by local leaders (who are also head of households), where the chronic cough was discussed. The meetings helped achieve a community-wide commitment to addressing the issue, which is followed up by FAC action. Specifically, FAC medical teams – composed of a doctor and technical auxiliaries (from communities and trained by FAC) – go to the villages and accompanied by their local health workers, examine all members of the families previously concentrated in a communal house by the community leader(s), while taking sputum samples of suspects for microscopy and cultures.

The results are given in presence of all families of the community, and the patient and his or her family makes a public commitment to complete the treatment. The village health workers are trained

to provide DOT, undertake contact tracing and administer prophylaxis, and the technical auxiliary teams conduct monthly follow-up visits to the relevant communities.

Subsequently, the doctors visit the patient during the transition from the intensive to the continuous phase of the process, as well as at the end of treatment. Health education is conducted throughout the visits, with the specific topics dictated by the patient, his/her family and the rest of the community.

Throughout the process, FAC and community leaders or village health workers prepare and use data monitoring sheets to document surveillance information an individual patient outcomes and use individual family cards for case holding.

Project results:

In total, the project enrolled 16 communities in the period 2006-2008. The effort reached 2407 people, with 406 sputum examinations and 380 cultures performed on 247 patients. Of those tested, 26 were identified as smear-positive for TB. All TB patients received treatment and, although one patient died, 25 out of 26 were successfully treated, resulting in a 96.6 % treatment success rate.

Lessons:

The intervention shows how strong community partnerships together with a local technical NGO can support effective TB control and treatment amongst poor rural populations living in small, isolated and geographically disparate communities, with coordinated follow-up ensuring a nearly 100% treatment success rate.

Vital elements of this project included the use of pre-existing social structures that enjoy trust amongst the indigenous populations, the display of overt respect for locally predominant traditions and a true understanding of long-held local beliefs concerning chronic cough. In good degree because of this sociocultural sensitive approach –involving leaders of community organizations from the very start – the TB case finding, holding and awareness-raising activities resulted in higher efficacy at lower cost of time and money than would have been achieved by creating new organizations to address the TB problem.

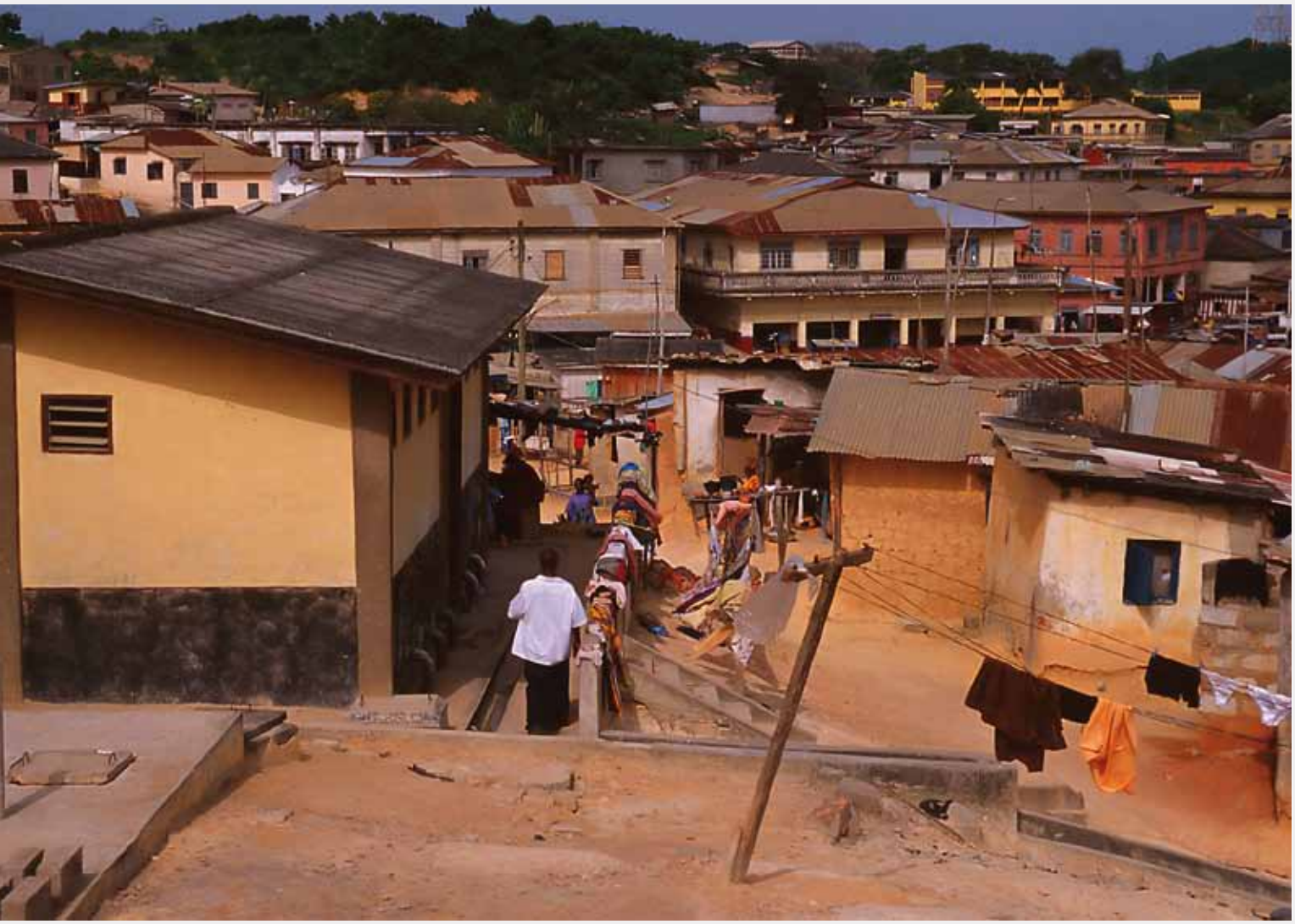
Ghana

Overcoming stigma
regarding TB by engaging traditional community leaders

Submitted by: Ghana Stop TB Partnership

Ghana Stop TB Partnership

The Ghana Stop TB Partnership (GSTB) is a multisectoral umbrella organization co-hosted and managed by the Ghana Society for the Prevention of TB and the Afro Global Alliance (GH). The partnership currently has a total membership of 150 NGOs, CBOs and such private businesses as laboratories, licensed chemical suppliers and pharmacies. The objective of the partnership is to support national and global plans to arrest the spread of TB. GSTB's main activities focus on implementing ACSM activities, training community treatment supporters, as well as engaging in behavioural change communication in communities to increase case detection rates and to reduce TB stigma and defaulter rates.



TB Control Challenge:

The Central Region of Ghana is one of the country's poorest. It also has the lowest treatment success rate in the country (51.1% in 2005[1]). Among the leading causes of this situation is persistent superstition on the part of the locals. For many citizens of the Central Region, TB is a spiritual disease. Its name is directly linked to that of a ghost, and contraction of the disease is attributed to *"juju"*, or offence against the gods, a perception that exacerbates the stigma of contracting it.

For these people, seeking medical assistance is a last resort, pursued only when the prescriptions of the fetish priest or herbalist have failed to reverse their symptoms. The consequent late reporting of patients for treatment is one of the contributing factors in Ghana's high TB death rate, which more than doubled between 1996 and 2004, when it reached 8.6%.

ACSM Solution:

To overcome the negative effects of TB stigma and non-treatment related to the region's heavy reliance on traditional customs and superstition, GSTB enlisted traditional community leaders as advocates to communicate correct messages about TB and TB/HIV.

The project began with district and regional meetings where the project goals were introduced and a baseline KAP survey of community members and traditional leaders was initiated. The KAP data exhibited indifference toward TB in general, with most people in the community viewing it as a phenomenon coming from the gods, against which little can be done. The data also revealed an overall lack of motivation to improve case detection and discrimination against TB patients by family, community members and health workers.

To address these issues, GSTB engaged traditional leaders with high status in their communities. These so-called "Kings" and "Queen-mothers" are able to influence local beliefs and behaviours – including those related to TB and HIV – while also disseminating appropriate information on basic TB issues and the importance of strict adherence to treatment.

One-day sensitization workshops were organized for the project managers to inform the local leaders about TB/HIV issues in their communities and to discuss their roles in the project. In all, 33 Kings and Queen-mothers agreed to become TB/HIV advocates.

In their new advocate roles, they included TB/HIV as an important community issue in their public addresses. Furthermore, Queen mothers also reached out directly to women, informing them about the importance of recognizing symptoms and seeking early diagnosis. With their assistance, traditional festivals showcased GSTB-designed TB information materials, and community meetings included frank, informative discussions on TB/HIV.

In addition to utilizing traditional moral authorities to advance awareness of TB issues and education, the project also sought to mobilize community volunteers and train them on TB and HIV issues through sensitization and ACSM training activities. This component was aimed at increasing community

[1] NTP Data.

participation in such TB-HIV activities as identifying TB suspects and using education to reduce the stigma and discrimination against people affected by both illnesses. Community case finding was also carried out by community-health volunteers to ensure a cohesive model of TB care, supported by information and education activities.

Approximately 860 community volunteers were recruited and trained by GSTP in collaboration with the NTP. In addition to supporting the leaders' advocacy efforts, they conducted home visits and provided TB services, including case detection, DOT supervision, defaulter tracing, follow-up and referral, TB education and, if needed, sputum collection. These volunteers reached over 900 000 people.

Another component of the ACSM programme was to build alliances with regional health staff, which was necessary for proper monitoring and evaluation of activities. Regional committees, with representation from community leaders and regional health departments, provided technical direction as well as monitoring support for this step, with district-level committees assisting in the planning and supervision of activities.

Project results:

Utilizing local moral authority figures in a region that previously had the lowest treatment success rate in Ghana was instrumental in achieving a 30% increase in the treatment success rate within the 2006-2008 period, helping the Central Region to attain the target rate of 85%. It also was a major player in the successful reduction of the defaulter rate, from 19.8% to 9.1%, as well as an increase of cases detected from 871 cases in 2004 to 1302 in 2006. Based on these positive results, the NTP has asked GSTB to expand the model to three more regions.

Lessons:

The GSTB case offers several important lessons, including how to successfully employ a national TB partnership to coordinate and partner with regional structures. Its biggest contribution, however, is found in its illustration of how the innovative use of influential stakeholders from traditional social structures can overcome high sociocultural barriers to early TB diagnosis and proper treatment. This innovation shows how case finding and treatment support activities benefit greatly from such political support, resulting in higher general acceptance of TB-HIV services.

India

Improving DOTS access in the poorest slum areas of Delhi through community-managed DOT centres

Submitted by: Operation Asha

Operation Asha

Operation Asha (the Hindi word for "hope") initiated operations in 2006 to combat the spread of TB in India. It is the largest non-profit TB treatment organization in India, operating centres within the slums that often can be reached only by foot. Since its inception, Operation Asha has worked with the inhabitants of some of the poorest areas in India, such as the rag-pickers' slum, where dwellers sort through garbage and typically earn US$0.20 – US$1 per day.


Operation ASHA
Op ASHA
DOTS CENTRE
डॉट्स केन्द्र

TB Control Challenge:

TB spreads quickly among families living in urban slums, where many live in unhygienic, poorly ventilated shanties. Other problems that exacerbate the spread of TB include HIV infection, severe malnutrition and recurrent infections, as well as a lack of comprehension of TB symptoms and inadequate availability of treatment. The spread of TB is also aided by a deep-seated fear of death from the disease, which contributes to an unwillingness to be tested for it, as well as the social ostracism TB patients often face.

Efforts to stem the spread of TB are hindered by a lack of access to DOT centres, which – even if they are accessible – are only open for a limited time, usually during normal working hours. Additionally, given the significant time, effort and money needed to reach the centres and the dire economic circumstances most slum dwellers face, many patients prioritize buying food for their families over paying for transport to seek diagnosis or treatment.

ACSM Intervention:

To recruit community members, private health-care providers and successfully treated patients to become DOT providers by establishing DOT centres in their private shops or homes or clinics within the hard-to-reach urban slum areas. The intervention is complemented by communication activities to increase early case finding.

Operation Asha set out to recruit slum residents and successfully treated TB patients and private health-care workers to act as DOT providers to increase case detection, reduce social stigma and ensure zero-default on treatment. Former TB patients from the slums represent a potentially important force in reducing TB-related stigma, as their positive example can not only motivate TB suspects to seek diagnosis (in large part by showing that the disease need not be fatal), but also other former patients and community members to become DOT providers.

Furthermore, because the slum residents typically provide DOT directly from their homes or shops (which are located in the midst of the communities and are therefore accessible to TB patients for a large part of the day), they greatly enhance access to treatment for residents who need to work.

For all centres, Operation Asha receives drugs directly from the Revised National TB Control Programme (RNTCP) and oversees distribution and inventory. Treatment follow-up services are provided by local government clinics to which people are referred as needed.

Other activities include extensive community outreach by Operation Asha's trained counsellors. They conduct home visits to families to provide TB education and refer suspects to diagnostic centres, as well as education sessions in schools, temples, religious places, weekly bazaars, community centres and factories.

As the DOT centres do not provide diagnostic services, TB suspects identified through these outreach efforts need to be referred to a local clinic or hospital. Upon receiving a confirmed TB diagnosis, patients can choose whether to receive DOT at the clinic or directly at the nearest community-managed DOT centre. Operation Asha, together with the slum community, also plays an advocacy role in engaging local politicians to support funding and resources for the establishment of more DOT centres within the community.

Operation Asha's counsellors monitor each individual patient and provide details to the RNTCP in various weekly, monthly and quarterly reports. Patients are followed thrice a week and reports document events adversely affecting treatment outcome, such as missed doses, defaults, transfer of patients to other DOT centres and other cities, deaths, and hospitalization if patients become ill. The final treatment outcome is recorded in government-operated clinics after the result of the final sputum microscopy sample.

Project results:

In the period 2006-2007, the defaulter rate in Operation Asha project areas in South Delhi dropped from 5% to 3%, whereas for all of Delhi, it rose from 6% to 8%. Since 2007, Asha has engaged over 2400 patients and currently operates 43 community-managed centres, with 125 more planned for 2010.

In communities or projects areas supported by Operation Asha, preliminary data for South Delhi for 2009 shows default rates dropping to 2%, while case notification nearly doubled.

Lessons:

Operation Asha illustrates how the community itself can play an active role in changing behaviour towards timely care seeking by those with TB symptoms, as well as in the TB treatment among some of the most vulnerable, impoverished and hard-to-reach populations in India: urban slum dwellers. The project also shows how using recovered TB patients as support providers can help lower the paralysing fear of the disease, as well as the stigma TB patients face in society, thereby reducing an important barrier to lowering default rates and increasing detection rate.

Malawi

Improving access
to timely diagnosis for TB suspects and PLWHA in communities with high HIV prevalence

Submitted by: Family Health International (FHI)

Family Health International

Formed in 1971, Family Health International (FHI) is among the largest and most established non-profit organizations active in international public health. Since its inception, the group has focused on improving lives around the world through research, education, and services aimed at promoting family health.

FHI, with funding from USAID and in collaboration with Management Sciences for Health, is implementing a joint TB/HIV project in selected parts of *Mangochi* and *Zomba* districts of Malawi. The organization's approach is to engage community-based HIV/AIDS groups to increase TB case detection rates and improve the quality of care that TB patients and PLWHA receive.


TBCAP

TB Control Challenge:

Problems in combating TB in Malawi include a high rate of HIV infection among TB patients (68%). This and delayed diagnosis of TB have contributed to high rates of TB mortality (102 per 100 000 in 2007 – Global TB Control Report 2009). Furthermore, there is little coordination between the TB and HIV programmes, leading to low uptake of antiretroviral therapy (ART) among TB patients and insufficient TB diagnosis services for HIV-infected individuals.

Malawians are poorly informed about TB and sufferers are doubly stigmatized due to TB and HIV and the links between the two diseases. At the launch of the project, the Mangochi and Zomba districts had reported persistently low TB case notification and high treatment default rates (5% and 8% in 2007, respectively).

A baseline survey was undertaken to identify gaps in the delivery of joint TB/HIV prevention, care and support services at the community level. Survey findings showed that multiple stakeholders are providing TB and HIV/AIDS prevention, care and support services at the community level in a mostly uncoordinated manner, leading to replication and reduced efficacy of efforts. TB diagnosis and treatment are also hampered by low TB knowledge in the community, limited availability of IEC material on integrated TB/HIV prevention, insufficient care and support activities and a high degree of TB- and HIV-related stigma.

ACSM Intervention:

The project worked to increase access to TB diagnosis and treatment in semi-rural areas by recruiting community volunteers to collect and transport sputum samples. These efforts were supported by systematic community IEC activities about TB/HIV co-infection, and the integration of TB treatment in home-based care.

In collaboration with the District TB programme, FHI established an effective referral network for TB and HIV/AIDS care and support, and implemented integrated TB/HIV activities, including those aimed at sensitizing the community about the dual epidemic. As part of this effort, district health officers also trained volunteers from community-based organizations and other extension workers on integrated TB/HIV prevention, care and support.

The project established community sputum collection points directly in project areas and provided bicycles and sputum-carrying containers for use by volunteers to transport samples. A joint office maintained a community chronic cough register, at which the details of all TB suspects and their sputum examination results were documented.

Once sputum test results were available, volunteers brought results back to patients. By instituting sputum examination sites at health centres within communities that have historically experienced difficulties in accessing health care services, the intervention reduces the delay in TB diagnosis typically related to long distances and long waiting times at health facilities.

Treatment of cases was supervised by guardians and volunteers from organizations that provide home-based care to people living with HIV, TB patients and others who are chronically ill. Separately, volunteers, including former patients and people living with HIV, conduct community awareness activities to promote early detection among TB suspects.

Much of the monitoring and evaluation supervision efforts were provided by the community mobilization specialist (an FHI staff member), who conducted monthly field supervisory visits to implementing partners. In keeping with the collaborative approach, a district TB officer and a TB/HIV focal point person from community health centres also participated in monitoring visits, documenting the number of

TB cases detected and admitted in home-based care, as well as the number of PLWHA who were screened for TB and referred to health facilities for TB diagnosis.

Project results:

Since the April 2007 launch of the project, participating community organizations have instituted integrated TB and HIV prevention, care and support services in the catchment area of 21 health facilities (as compared to no integrated services prior to the initiative). The project, which is due to conclude at the end of September 2010, has recruited 82 former TB patients and 769 people living with HIV to participate in community sensitization efforts, while 1741 TB suspects have submitted samples though the community sputum collection points (with 173 (10%) producing a smear-positive test result). Separately, another 278 people living with HIV have been referred for TB screening, 101 (36%) of which were found to have TB.

Lessons:

The case exhibits the benefits of building linkages between the TB and HIV activities directly at the community level to create greater coordination for delivery of care and to improve support mechanisms for patients and people affected by both epidemics. It also shows how home-based care organizations can reduce the negative effects of TB for all community members through active participation in integrated TB/HIV prevention, care and support activities. The impact is highest in settings with a high burden of TB and poor accessibility to health services.

The ACSM activities also mobilized the community to participate in integrated TB/HIV prevention, care and support to improve community knowledge on TB and HIV and to improve access to TB diagnostic services. They proved effective at promoting collaborative district and community planning and implementation of TB/HIV activities.

Finally, the sputum transport support system proved to be a vital tool to help achieve early detection in areas where the absence of laboratory and diagnostic capacity is a crucial bottleneck for early diagnosis, particularly for weakened HIV patients.

Mexico

Transforming a medical model for TB using community-centred approaches to improve detection and treatment success rates

Submitted by: Project Concern International (PCI)

Project Concern International

Project Concern International is a non-profit health and humanitarian aid organization dedicated to preventing disease, improving community health and promoting sustainable development.

Together with the Institute of Public Health Services (ISESALUD) for the state of Baja California, PCI implemented a four-year USAID-funded project, SOLUCION TB (Strengthening Observed therapy Linking-Up Community-based Integrated Outreach Networks for TB control). Initially based in the state of Baja California, the project's success there led to its expansion to the 13 Mexican states where incidence is highest (cumulatively accounting for 65% of the nation's cases).

TB Challenge:

Mexico continues to struggle to contain the spread of TB. In 2008, the National TB Programme (NTP) reported 18 810 new cases (all forms), of which 92% were smear-positive new pulmonary cases. Among the more pressing challenges in TB control are the chronic delays in the seeking of care and low treatment adherence rates. A high rate of co-incidence with diabetes mellitus and HIV also contribute to country's high rates of TB morbidity and mortality.

The challenges of effectively responding to and containing TB are compounded in the northwestern state of Sonora, owing to its unusually high rates of mobility and migration – both within Mexico and to the US – as well as its desert topography. The migratory patterns, prevalent in Sonora in particular, challenge efforts aimed at promoting greater treatment adherence and effective outreach to encourage people with respiratory symptoms to seek clinical diagnosis.

ACSM Intervention:

At the centre of the Mexico-wide *SOLUCION TB* programme was an enhanced focus on patients. This person-centred approach significantly contributed to lowering the stigma against TB patients, by humanizing people with TB in the eyes of both health services providers and the general population. Greater societal acceptance of TB patients has, in turn, encouraged greater participation by these people, who have a unique role to play in increasing detection and treatment adherence.

Thus encouraged, TB patients publicly shared their TB experiences through highly effective forums, conferences, media interviews, support group meetings and training workshops for health staff.

The project has also helped raise awareness of the disease. By making TB patients more effective ambassadors, they have made significant strides in helping: TB patients receive better treatment by health personnel; suspects seek more timely obtainment of diagnoses; and state government officials dedicate more resources for TB control programmes.

Also notable among the project's interventions was its use of the "Photovoice" component. Employing photography and narratives of people afflicted with TB, the programme played a vital role in humanizing the disease and educating decision-makers, health-care providers and the public at large on what TB means for those who are affected by it.

The intervention's television videos, radio spots and Photovoice ("Voices and Images of TB") exhibitions formed a critical component of World TB Day, which reached more than 500 000 people and was instrumental in a noticeable increase in the number of people submitting themselves for testing. It also was a major factor in the Secretary of Health for Baja California declaring that 2009 would be "The Year of TB control".

The ACSM element of SOLUCION TB also entailed outreach activities with messaging specifically tailored – in both content and dissemination technique – to achieve maximum impact in each of the 13 provinces.

In Sonora, support groups combined with innovative awareness-raising approaches to achieve extremely positive effect. Outreach approaches used to their advantage both the high rate of migrant workers in

the state and leaving it,as well as the relatively high rate of participation in faith-based activities. One initiative saw project staff undertake a programme of TB messaging in which they made presentations to the many people standing in queue at administration centres, as migrant status requires frequent visits to municipal agencies to satisfy documentation requirements.

Similarly, approaching clerical authorities for cooperation resulted in TB information being included in weekly church bulletins, speeches and individual outreach efforts conducted at the church exits. The positive results of these presentations led to church officials becoming more proactive partners in the effort to educate their constituents about TB, inter alia, disseminating information that aids citizens in identifying the disease's symptoms.

Advocacy efforts saw TB patients successfully lobby state officials and decision-makers for logistical support, as well as help with information dissemination efforts. In response to the latter, the Sonora Government broadcast TB messaging at carnivals, sporting events and parades, as well as on billboards in major cities.

Project results:

The ACSM efforts played a major role in a significantly enhanced number of Sonorans receiving microscopy at health centres, from 1301 patients tested in 2007 to 2337 in 2009, a 79.6% increase. Similarly, the number of new cases detected rose from 45 in 2007 to 94 in 2009, a 108.8% increase.

In the same way, the project's advocacy initiatives resulted in the donation of an ambulance and a motorcycle, vehicles that have directly led to improved supervision of cases, and, consequently, greater treatment adherence. Treatment default rates in Sonora were reduced by more than 50% and the treatment success rate rose steadily, from under 34% in 2005 to 69.5% in 2006 and 84% in 2008.

Lessons:

Among other lessons, the *SOLUCION TB*'s Sonora programme highlights the benefits of tailoring each ACSM activity to the target audience. Innovatively harnessing the captive-audience nature of the state's well-subscribed municipal documentation service, as well as Mexico's generally high rates of church attendance, the project reached people it otherwise may well not have.

Furthermore, the empowerment of TB patients helped that stakeholder group to more forcefully share the experience of living with TB with a wider audience. This process directly led to a reduced stigmatization of the disease by health providers and the general public, as well as enhanced levels of state support for preventative programmes.

Moldova

Planning and implementing effective Public Awareness Campaigns (PACs)

Submitted by: Centre for Health Policies and Studies (PASC)

About Centre for Health Policies and Studies (PAS Centre)

PAS Centre is an independent, not-for-profit, Moldovan organization. It undertakes various public health projects in the country, including initiatives aimed at promoting enhanced local capacity to confront HIV/AIDS and TB, as well as those to institute improved financial management and reporting practices amongst health-care providers. The group is the second principal recipient of the Global Fund grants (Round 6 and 8 on TB control and Round 8 on HIV/AIDS). In 2007, PAS Centre succeeded the American International Health Alliance (AIHA) as the lead implementing agency for TB control activities in the country.


171
Nu Fiți Indiferenți!
Susțineți Bolnavii de Tuberculoză!
USAID
TUBERCULOZA
POATE FI TRATATĂ!

TB Challenge:

As in most former communist bloc countries, the epidemiological TB situation in Moldova deteriorated sharply after the collapse of the Soviet Union. The spread of TB reached epidemic numbers in the 1990s due to a socioeconomic crisis, insufficient financing of the health-care system and a lack of anti-TB drugs in the country.

While progress has been made since 2001, when the Government of Moldova established its NTP and began implementations of DOTS, TB still affected 108.3 per 100 000 of the population in 2003. Greatly contributing to the persistently high rate of incidence was a severe misunderstanding about TB on the part of both the general public and health workers. Among the causes for this situation was the fact that no nation-wide TB-specific IEC activities had been carried out in the country for more than two decades.

ACSM Intervention:

The project implemented a two-pronged strategy in the 2004-2008 period, working to improve the knowledge and practices of public health-care givers while also conducting eight public awareness campaigns (PACs) throughout the country. In each intervention, PAS Centre tailored its messaging and information packages to the needs of the target audience in the nation's different districts and regions.

Before planning the interventions, the project undertook a KAP survey of 1194 Moldovans over the age of 18 to gauge the national awareness and understanding of TB. Key findings revealed that, while most were familiar with the main symptoms of TB, they had weak knowledge on the mode of transmission, did not believe that TB could be cured and were unaware that treatment was free of charge. There was also weakness of TB knowledge among primary health-care providers, especially regarding the value of DOTS activities. They also did not fully understand their role in TB control, which they viewed as being limited to case detection.

Based on the findings, the project elected to focus on activities to raise Moldovan awareness of TB as a curable disease (in order to both increase care-seeking behaviour and to reduce the disease's stigmatization) and of the fact that diagnosis and treatment are offered free of charge.

The first step taken before implementation of activities was to develop the materials and train the people who would be carrying out the activities. The first half of this process entailed developing a branded communication kit, including such multimedia IEC materials as educational videos and brochures, poster calendars and communication guides designed for different audiences.

The PACs were conducted so that each one reached its audience with a specifically tailored message, while always making a central theme that "TB can be treated". Some of the campaigns focused on primary health-care workers to help improve knowledge of DOTS and TB diagnosis and treatment, some targeted the general population in districts burdened by high prevalence of TB and HIV/AIDS, while others focused on reaching such vulnerable groups as Injection Drug Users (IDUs) and People Living With HIV/AIDS (PLWHA).

Each of the campaigns consisted of a series of events conducted over 2-3 months. The events included television and radio broadcasts of brief educational segments, programmes to distribute printed materials and initiatives to have informational teams and NGO volunteers conduct meetings with the public or target groups.

The project directed a media campaign that was at once graphically uniform across the nation, but which featured different messaging for individual target groups. Using *positive language* it worked to: 1) lower the stigma endured by TB patients, a group commonly associated with the lowest echelons of society; and 2) raise awareness that TB is an entirely curable condition and that treatment is free.

The campaigns, which featured widely disseminated posters with such messages as "Tuberculosis can be cured! TB patients need your help!", and "Tuberculosis can be cured! TB diagnostics and

treatment in Moldova are free!" were designed to increase the detection rate and also introduce a more patient-centred approach to TB care.

The programme utilized numerous channels of communications, including TV, radio, NGO workers, journalists and medical practitioners. It also placed flyers and informational material in such heavily trafficked locations as post offices, social service agencies and on public transport. Because of the wide range of materials it distributed through myriad mediums, the PASC logo – a dandelion – is among the more recognizable logos in the country, widely associated with the TB cause.

Project results:

The project managed to largely increase the level of public awareness of TB, its causes and the availability of free treatment, within a relatively short period of time. A comparison of the results of KAP studies conducted in 2004 and then in 2008 reveals numerous indicators of heightened understanding of the disease. For example, the percentage of surveyed people who understood that coughing is a leading cause of transmission increased by 16.4 points to 78.2%.

Even more impressively, the share of Moldovans who understood that TB can be treated more than trebled, rising from 12.9% of those surveyed to 39.3%. Likewise, the number of people who believed that the disease was untreatable or were unsure on the question dropped from 28.4% to only 11.6%.

The rise in public consciousness of TB and its effects and causes directly contributed to the formation and official registration of Speranta Terrei, the country's only NGO comprised of former TB patients. The group's work with current patients and their relatives has been highly successful in advancing the cause of a patient-centred approach to TB treatment.

Lessons:

The project showed how well-designed and -executed ICE strategies can address a massive lack of public understanding of vital issues of TB (e.g. cause of transmission, likelihood of treatment success) in a short period. Using the PAC to directly confront the leading obstacles to higher treatment success and detection rates (stigma and a belief that TB is necessarily fatal) was instrumental in changing public attitudes.

Philippines

Bulacan Province:
Increase in TB case detection through community anti-TB task forces

Submitted by: Provincial Health Office, Malolos, Bulacan Province

Provincial Health Office, Malolos, Bulacan Province

The Provincial Government of Bulacan [PGB] works to promote the general health and well-being of its constituents by ensuring accessibility, affordability and availability of quality health care services that helps individuals and their families to source productive, self-reliant and self-managed community solutions.

The group undertakes critical strategic initiatives focusing on increasing investments in public health programmes and projects, ensuring quality service and accessibility of health care facilities, expanding Philippines Health Insurance Corporation's coverage for indigent families and the non-poor, among others.

In implementing the national government's Health Sector Reform Agenda, PGB adheres to the "FourMula One" framework for improving the delivery of health services by focusing on strengthening health-related systems, financing, regulation and governance. The Province-wide Investment Plan for Health (PIPH) shall serve as a channel in the implementation of much-needed health reforms in the various levels of governance.


075
CDI-125

TB Control Challenge:

Although the Bulacan Government has vigorously followed the National TB Control Programme, TB has remained one of the 10 leading causes of mortality in the province for the last five years, with the disease plaguing a sizeable segment of the population.

The province features one of the highest rates of TB prevalence in the Philippines. The case detection rate (62%) and cure rate (81%) remain well below the national averages (75% and 85%, respectively). The province also has a relatively high TB mortality record, with annual deaths ranging from 367-439 in the 2005-2008 period.

Low case detection is exacerbated by a lack of strategic activities at the local level, as well as weak programme management skills of providers, particularly in monitoring and supervision, programme planning and communication. The province's low treatment success rate owes in significant part to a lack of effective strategies in patient follow-up during treatment, which results in low levels of sputum examination and compliance to daily intake of prescribed medications.

ACSM Solution:

Forming an "anti-TB task force" to undertake a coordinated programme aimed at strengthening TB control activities at the community level. Some of the task force's specific mandates included fostering public policies that support local initiatives, and developing the skills of both health workers and community volunteers to detect cases of TB and to educate Bulacan locals in how to halt its spread.

The provincial health office staff, which was charged with the implementation of the programme, involved various community groups in the planning and implementation of the project, including the council of the local Catholic church parish, women's groups, Rotary club, local schools, *barangay* (village) volunteers and health workers.

Together, they developed the idea of the taskforce, which they christened "the *Barangay* TB Patrol" (BTBP), consisting of a mix of community leaders and health workers who provide TB education and case finding services in areas marked by exceptionally low case detection.

The task force members are charged with: 1) formulating TB health plans in coordination with municipal health offices; 2) educating clients (TB suspects and patients) on basic TB facts, misconceptions and DOT treatment protocols; 3) identifying and referring TB suspects to DOTS centres; 4) acting as treatment partners; and 5) serving as a TB advisory group for the Barangay Council on TB-related matters. In total, the project established BTBPs in 14 barangays, with 98 members (seven members for each team).

Trained in TB and DOTS, BTBP members also received instruction and guidance in awareness-raising techniques, conducting house-to-house campaigns to educate community members on TB and DOTS and on how villagers can identify TB suspects and refer them to DOTS centres. The BTBP

also distributed TB information materials during each home visit, held community assemblies to disseminate TB information and coordinated a TB health exhibit in seven hospitals.

Monitoring support was provided using a simple referral form and return slip to document diagnostic outcomes. Quality assurance teams from the provincial health office conducted regular DOTS facility assessments to ensure correct standards and procedures and to provide feedback. Focus groups were also carried out with BTBP target clients to determine how they viewed the project and whether it could be made more locally appropriate.

Project Results:

Members of the BTBP visited 7169 households for a total reach of 41 974 individuals, representing 71% of the population in the project sites. In total, more than 600 TB suspects were identified and referred. The pool of referred included 41 locals (6.8%) who were diagnosed as new smear-positive cases and who were started on TB treatment (outcomes not available yet). The provincial government is now expanding the project into 47 barangays marked by low case detection and cure rates.

Project Lessons:

The Bulacan case shows how a provincial TB programme can mobilize a community to play a key, active role in the effort to change behaviour in areas that have been persistently "silent" (i.e. where TB patients have historically failed to seek diagnosis). The task force approach serves as an important model for finding TB suspects and for encouraging early detection and adequate treatment.

Furthermore, the concerted engagement of communities in intervention planning and implementation enabled much wider-reaching impact than has been achieved by initiatives that are obviously foreign-led, as demonstrated by the number of households reached by task force members.

Philippines

Maguindanao Province:
Increasing access to microscopy in a conflict setting

Submitted by: Catholic Relief Services - United States Catholic Conference of Bishops (CRS-USCCB)

Catholic Relief Services

Catholic Relief Services (CRS) has been working in the Philippines continuously since 1945, when it launched relief and reconstruction efforts in the aftermath of World War II. In addition to responding to natural and man-made emergencies, CRS Philippines also undertakes work in the areas of peace building, health and agriculture or natural resource management.


ANG DEP ED NG PAOMBONG
AY NAKIKIISA SA PAGLULUNSAD NG:
BARANGAY TB PATROL
KAAGAPAY N'YO SA
TB KONTROL
BUWAN NG MALUSOG NA BAGA
• AGOSTO • 2008 •

TB Control Challenge:

Although the province of Maguindanao has achieved case detection and treatment rate improvements that bring it close to the national average, sizable gaps remain among its 33 municipalities. The underperformance of some of them owes to several factors, most notably including ongoing armed conflict in the province.

This situation has led to the displacement and evacuation of families, events that adversely affect the implementation of TB activities. TB control efforts are further hindered by a lack of coordination between private facilities and rural health units (RHUs), and a serious lack of necessary health personnel, including insufficient staffing of public health facilities.

ACSM Intervention:

The project worked to leverage local resources to improve TB care-seeking behaviour and community access to microscopy and DOTS services.

CRS's Maguindanao Tuberculosis Control Project (MTCP) was a four-year project implemented in partnership with the Integrated Provincial Health Office (IPHO) with the goal of significantly reducing TB morbidity and mortality by 2009. Implementation occurred in 33 municipalities, serving 475 056 individuals aged 15 years and above. By the end of the four-year project, it had detected more than 4250 smear-positive cases.

At its inception, the project identified major gaps and challenges in implementation of TB control activities that could be effectively responded to with ACSM initiatives. Some of the barriers to the delivery of TB care included:

- health staff and volunteers' technical competency in the areas of TB prevention and control were badly out of date;
- irregular supervision and monitoring of provincial and municipal staff for provincial TP;
- poor access to health services for community members caused by the ongoing conflict, lack of health personnel and difficult geographic terrain;
- limited community knowledge on the causes and transmission of the disease; and
- societal stigma related to TB.

From the outset, the project had to factor in the volatility of the security situation caused by the protracted armed struggle of Moro separatist groups. To respond to periodic escalations of the conflict, the project worked with the IPHO-Maguindanao's Quick Disaster Response Team (QDRT, a unit composed of health professionals who respond to emergency situations) to track patients and defaulters.

Additionally, the project conducted a rapid assessment of the impact on the programme caused by the displacement of some communities from the province, tracking patients who had either been placed in evacuation centres or were house-based to ensure treatment compliance.

Catholic Relief Services and the Integrated Provincial Health Office developed an ACSM strategy to address obstacles to TB diagnosis, treatment and care identified during the baseline survey. Notable among these barriers was the behaviour of health workers – who exhibited indifference towards TB patients and a reluctance to interact with them – which was lowering the quality of TB preventive and curative services, specifically by not adequately encouraging adherence to DOTS treatment protocols by both TB patients and caregivers. The strategy also included advocacy efforts, lobbying local government units to make TB prevention a priority and to allocate the needed resources to the project.

The project also engaged existing community support groups to assist in DOTS implementation, particularly in providing TB information and improving patients' access to DOTS facilities. This multi-channel approach drew on a variety of methods and materials and focused on the target audience, giving consideration to the needs, culture, and on-the-ground realities in Maguindanao.

To inform project implementation, CRS carried out several baseline surveys covering the general population, health staff, private sector physicians and health volunteers. The survey indicated, inter alia, that doctors, nurses and midwives practised inconsistent application of DOTS protocols in their daily work, that community health workers were not supervising treatment compliance and that TB patients were not thorough in taking their medicine as prescribed.

The security situation naturally was chief among the local complicating factors. Among the project's response to it, was greater emphasis on community-based TB care services, which would be critical for those who could not travel due to security risks.

Responding to the findings of the baseline assessments, the project added several new activities, including: ACSM workshops (including one focusing on behaviour change communication for health staff); reactivation of 11 local health boards to plan and solicit for greater political support for TB; and the development of several community-engagement and patient-empowerment approaches to improve case finding and treatment success rates.

To promote greater cooperation between care providers and receivers and instil a greater sense of community investment in its success, local health staff, patients and community members were asked to participate in all aspects of strategy implementation.

The programme's ACSM components included: helping service providers to conduct individual counselling of all patients prior to the initiation of treatment (this was achieved by training them in counselling skills and reallocating duties to minimize the work overload that was previously obstructing counselling efforts); regular TB education sessions at the health centre for patients; and home visits by health volunteers to track those who abandon treatment and counsel patients and family members to prevent default.

The project also supported the formation of TB clubs for people under treatment, with cured patients serving as counsellors. Seven TB clubs with an average of 6-12 members each were established and conducted regular meetings. The composition of the individual clubs was constantly changing, as new patients would enrol and successfully treated patients would "graduate" out of them.

To expand diagnostic laboratory services to the community for increased case finding, the overburdened workforce of 10 medical technologists serving the province's 33 municipalities was supplemented by 168 *barangay* (village) health workers (BHWs). The BHWs were trained in sputum collection and smearing, with provincial and municipal TB coordinators monitoring and supervising their efforts using standard NTP monitoring tools.

Project Results:

During the course of project implementation, the number of TB suspects who received diagnostic services rose by 52%, from 3988 in 2005 to 6065 in 2007. The newly formed corps of BHWs played an important role in this success, referring 2178 TB suspects, of whom 374 (17%) were found to be smear-positive. Case detection rates in the province also showed significant improvement, increasing from 47% in 2004 to 86% in 2007, while the rate of default fell from 6% in 2004 to 4% in 2007.

The project also had a demonstrable impact in enhancing societal understanding of TB. The pre-intervention KAP survey showed 58% of the respondents believing that avoiding all contact with people with TB symptoms was appropriate behaviour, while only 18% expressed sympathy for TB sufferers and 32% believed that a TB patient should be treated like a normal person. By the end of the project, the percentage of people who avoided contact with TB sufferers had fallen to 44%, while those feeling sympathy for TB patients had risen to 51% and those willing to treat the TB-afflicted as normal had grown to 69%.

In good part as a result of the above, the provincial treatment success rate rose from 74% in 2004 to 78% by 2006, while treatment success rate improved from 88% in 2004 to 91% in 2008. By the end of the project, 23 of the 33 target municipalities exhibited improved treatment success rates.

Lessons:

CRS employed a multi-faceted approach to combating low detection rates in a conflict-prone region. By using a strategic ACSM approach, the organization was able to leverage significant community and local health resources to greatly increase access to microscopy and DOT services for people living in geographically isolated areas. The method of training lay people to identify TB suspects proved especially effective, accounting for a substantial share of the TB sputum-positive detections.

Romania

Empowerment of Roma peer health educators to improve TB knowledge and case finding in a disenfranchised population

Submitted by: HealthRight International (HealthRight) [2]

About HealthRight International

HealthRight International (HealthRight) is a global health and human rights organization working to build lasting access to quality health services for excluded communities. With support from USAID, the Open Society Institute and the Global Fund to Fight AIDS, Tuberculosis and Malaria, the organization worked in Romania between 2003 and 2008 to implement a TB control project in cooperation with and benefitting several groups, including primary care providers, TB patients and their families, and poor or excluded communities, especially the Roma.

[2] HealthRight International, founded by the late Dr Jonathan Mann, was known as Doctors of the World-USA from 1990 to 2009.


39

TB Control Challenge:

Although Romania has made consistent efforts to reduce the spread of TB, it continues to face a number of considerable TB prevention and control challenges. Significant among these are disparities in the level of TB burden and access to care among key vulnerable populations, notably the Roma, Romania's (and Europe's) largest single minority group. (The 2002 census reported that there are 535 140 Roma in Romania, although some reports suggest there are as many as 2.5 million.)

While TB data is not disaggregated by ethnicity in Romania, studies suggest that the Roma endure a disproportionately heavy TB burden, ranging from two to seven times as high as that of the general population. This situation owes to a variety of causes, including stigma against the group by health-care providers and the general public, the group's often substandard living conditions and the difficulties they face in satisfying the bureaucratic requirements needed to receive treatment.

ACSM solution:

The project worked to build capacity within Roma communities by training Roma peer educators to: improve TB-related knowledge; enhance community members' ability to surmount the legal obstacles to accessing pubic health services; and develop capacity for community-led advocacy initiatives by building skills, mobilizing stakeholders and devising advocacy strategies that create a policy environment conducive to promoting Roma health. The project also worked to promote more receptivity towards the Roma (who often face discrimination throughout society) by doctors and nurses, in an effort to improve client-provider relations.

The two-year project was implemented in Bucharest-Sector 5, Ilfov County and Neamt County, all areas with large, underserved Roma populations. Some of the gaps directly addressed by the HealthRight strategy included: a severe lack of quality TB information materials, especially for a low literacy audience such as the Roma; gross racial discrimination against minority groups at health facilities; substandard living conditions and poor knowledge regarding TB and other health problems.

A baseline KAP survey revealed that more than 50% of the surveyed Roma were not registered with a general practitioner, which is a prerequisite for being able to access any health services. It also showed that TB knowledge amongst Roma was the lowest of all groups surveyed – only 15 to 30% (rural to urban) were able to name any major TB symptoms, and fewer than 50% were aware that TB is treatable.

In partnership with a local NGO, Romani Criss, HealthRight selected 25 Roma men and women to serve as peer health educators (PHEs). The PHEs were trained to identify TB suspects and refer them to the nearest health facilities, and also to educate their community members about TB and DOTS. The awareness-raising activities included the preparation of informational materials – like educational films – tailored to meet the requirements of people with low literacy levels.

The PHEs also conducted sensitization training with over 700 general practitioners and nurses working in the project areas to reduce discriminatory attitudes historically faced by the Roma.

An important element of the project included helping the Roma develop advocacy skills to obtain their health-care rights and overcome the bureaucratic impediments. These efforts included an initiative to assist them in lobbying local municipal authorities to streamline registration procedures so Roma could more easily receive their identification and/or social assistance papers, documents that are needed to register with a general practitioner.

At the conclusion of the project, 12 PHEs from Neamt County formed a community-based organization known as the Centre for Community Development to continue health access improvement and advocacy efforts in their areas.

Project Results:

PHEs carried out 480 intensive three-month community education sessions, reaching 11 530 people. The project identified 607 TB suspects who were helped to access diagnostic services, a process that often entailed accompanying them to a clinic, as the Roma have limited experience visiting health-care providers. Of those tested, 49 (8%) were found to be TB positive.

Project Lessons:

The HealthRight case illustrates how a multi-faceted, specially tailored strategy can achieve significant gains in case detection and treatment completion rates, even amongst a poor, historically disenfranchised population.

Among the enabling factors of the project's success was the recruitment of capable members of the beneficiary group. With training and consistent monitoring support, the Roma PHEs capably served as TB educators, case finders and community advocates. Building on the community's wide acceptance and support of the HealthRight strategy in Neamt County, the PHEs formed their own organisation and have continued their work after the conclusion of the project.

Sudan

Utilizing partnership between NTP and community-based organizations to expand activities for TB control in (post-) conflict areas

Submitted by: National TB Control Programme

National TB Control Programme

The Sudanese TB control programme adopted the DOTS strategy in 1993 and began establishing model DOTS sites in 1996. Experience from these model sites led to 100% DOTS coverage from 2002. DOTS expansion was supported by training and intensive supervision. Quality assurance systems included the re-reading of sputum smears, peer-review by the TB laboratory co-coordinators to evaluate results and suggest amendments to activities undertaken by the programme coordinators, as well as systematic evaluation of routine programme reports. The expanded programme now provides DOTS services as part of primary health care through hospitals, health centres, selected health stations and designated NGO clinics.

TB Control Challenge:

Sudan accounts for 15% of the TB cases in the Eastern Mediterranean Region. Some of the main challenges facing TB control in Sudan are low case detection, high default rate (7.4% in 2007), a large number of conflict and post-conflict areas, high – and steadily rising – rates of MDR-TB and TB/HIV, poor collaboration (including notification) between the public and private sectors and high rates of turnover of state-level health staff.

South Kurdofan, site of the project, is an extremely poor state, with large conflict and post-conflict areas. The state has a high prevalence of HIV/AIDS, is largely uncovered by the health system and its residents have limited understanding about the causes and treatment of TB.

ACSM Intervention:

The project strived to form key partnership with existing civil society organizations, such as Women's Union and a patient association, to provide socioeconomic support to improve case detection and treatment completion. The intervention also undertook advocacy and awareness-raising activities to attract government attention to the alarming spread of TB in the state, and to garner official support to halt it.

The NTP and partners employed ACSM approaches to tackle some of the barriers experienced during the implementation of TB control activities, including low awareness of TB amongst the general population (which directly contributes to diagnostic delays), high stigmatization of the disease and significant defaulter rates among patients. Furthermore, although patients usually do seek health care from private and government health facilities, stigma and misinformation still lead many to consult traditional healers as their first point of care.

To overcome these barriers, the NTP formed key partnerships with the Women's Union and with the Sudanese TB Patients Association (STPA, a patient support organization that maintains a presence in 12 states), and provided their respective staff with TB training. Trained women, who typically enjoy a comfortable rapport with other females on the subject of health issues, carried out awareness-raising activities with community women, conducting meetings, group discussion, visits to people's homes and TB centre.

The STPA organized orientation sessions with TB patients, including sessions in which they shared their experiences with the community. The association also conducted home visits to provide social and psychological assistance to TB patients, and offered microcredit support to help them generate income.

Other project activities included efforts to provide a more comprehensive ACSM model, including the distribution of TB IEC materials through various outlets and community leaders, media advocacy, TB education campaigns in post-conflict areas and the broadcast of educational programmes over TV and radio. The groups also engaged in targeted advocacy efforts aimed at encouraging local health departments and politicians to increase the number TB/DOTS centres.

Project results:

Thanks in large part to the advocacy programme, TB was designated a priority in South Kurdofan. This helped generate an increase in the number of TB centres, from five in 2006 to 12 in 2008, and a 37.4% rise in number of cases notified, from 318 to 437, during the same period.

Lessons:

The Sudan case highlights the utility of forming partnerships with community organizations to increase awareness, reduce stigma and patient delay under post-conflict circumstances. Women's associations are particularly logical partner candidates, as women usually serve as the de facto caretakers and represent an at-risk community, especially in the context of HIV. The formation of

such alliances and partnerships can serve to support NTPs to advocate with (local) governments for the expansion of services into difficult-to-reach areas.

The project also illustrates the benefits of engaging TB patients, a step that helps reduce local fears and stigmatization of the disease and TB-affected persons. This step and the development of partnerships with CBOs were shown to be effective means of promoting timely diagnosis and treatment-seeking behaviour. This holds especially true in post-conflict settings, where such behaviour is the exception to the rule, due to the long absence of services.

Tajikistan

Developing
and implementing a national TB communication strategy

Submitted by: Project HOPE

Project HOPE

Project HOPE is an international non-profit organization that develops and institutes long-term solutions to pressing health problems. As a Principal Recipient (PR) for the Global Fund Round 3 grant and an implementing agency for USAID in Tajikistan, Project HOPE is continuing to actively participate in TB control activities and assist the NTP in strengthening all elements of TB control programme that are necessary for successful DOTS implementation.


STOP TB KIT

TB Challenge:

The post-communist social and economic disruptions of the 1990s brought TB control efforts in Tajikistan to the verge of collapse: many TB cases went undetected, treatment was largely unavailable and the rate of TB-related mortality experienced significant increases. External partners and the government initiated DOTS efforts to reverse this situation in mid-2002, and achieved 32% reach of the total population by 2004 and 100% DOTS coverage by 2007. However, large gaps existed in the availability and quality of TB informational materials for health personnel, TB patients and the general population. Furthermore, a legacy of the former communist system was that providers' technical and communication skills were very poor and non-patient friendly.

Efforts to raise awareness among Tajikistanis about TB symptoms and relevant treatment issues were undermined by a lack of coordination amongst the groups undertaking TB control activities. When IEC activities were conducted, the implementing organizations each produced their own materials without communicating with counterpart groups, a practice that led to confusing message inconsistencies.

ACSM Intervention:

The development and implementation of a national TB communication strategy by members of an ACSM thematic working group under the NTP, with technical assistance from Project HOPE and Johns Hopkins University. The development of this strategy encouraged greater coordination among the stakeholder agencies involved in TB programming and built the capacity of key policy-makers and implementing agencies through practical on-the-job training.

In order to effectively gauge communication gaps, the project conducted a comprehensive baseline assessment. The exercise consisted of a KAP survey of health providers, TB patients and the general population, as well as focus group discussions with TB patients.

The findings revealed an urgent need to help health-care providers improve the quality of their IEC activities with TB patients. Nurses in particular were shown to require better training, with 84% of those surveyed exhibiting inadequate knowledge of the disease. Patients also demonstrated a low level of comprehension of TB, with nearly 19% of respondents believing a five to six-month stay in hospital was required, and 70% unaware that TB treatment is free in Tajikistan. The fact that patients were clearly shown to be not adequately absorbing the facts delivered by health-care providers indicated that better methods of disseminating information were needed.

To overcome these barriers, the project coordinated training and guidance for members of the ACSM working group on: development of a TB communication strategy; development and pre-testing of IEC materials; and monitoring and evaluation of communication activities.

The national TB communication strategy targeted a variety of audiences for communication training and included the coordination of several community-oriented education activities. Those trained under the strategy included 40 TB hospital nurses (who received interpersonal communication/counselling skills training), as well as approximately 300 community volunteers and leaders, who were trained to carry out health education sessions for the general public.

The project also entailed a programme under which trained nurses implemented an in-service counselling programme to support treatment providers. Project staff also developed IEC materials – including booklets, brochures, posters and video and radio PSAs – that were aimed at both TB patients and the population at large.

The project also facilitated the creation of TB toolkits for use by patient education providers, including a diagnostic algorithm, a booklet on sputum collection, and a brochure on TB drugs' side effects and how to treat them. To make presentations more effective, the initiative also developed flipcharts explaining optimal techniques for patient treatment and counselling.

Additionally, community leaders were selected and trained to work with the general population to provide key messages on TB and to assist medical workers with DOT by taking TB drugs to patients who were unable to travel to health facilities to receive their daily dosage.

The project also conducted a media programme, under which it developed and broadcast TB public service announcements on radio and TV. The media programme included annual workshops for journalists to promote coverage of TB issues, including an organised visit to a regional TB hospital to interview medical staff, patients and visitors. The programme resulted in 29 articles being published on TB problems and on the necessity of social mobilization.

Project Results:

At the community level, 5780 community volunteers and leaders were trained, enabling them to effectively reach more than 700 000 people through coordinated IEC activities. Volunteers also assisted 1519 TB patients in DOT; their efforts included a programme to facilitate the administration and supervision of medication for patients who lacked ready access to health facilities and health education, a step aimed at decreasing the numbers of defaulter cases. At the health facility level, 128 TB and PHC nurses were trained in interpersonal communication and counselling skills.

Additionally, the quality and effectiveness of reaching the general public with TB information through mass media was improved by training 104 journalists from national and oblast (regional) television and radio stations and print newspapers, exchanging relevant information on TB and its treatment, This intervention enabled the project to reach a sizable percentage of the country's 6.7 million people.

The most important end result is a population significantly better informed about the causes, effects and aspects of treatment of TB. This phenomenon is illustrated by a 2009 post-intervention KAP survey, which, inter alia, showed that only 7.6% of those surveyed believed a five to six-month hospital stay is required (versus 19% who believed that in a pre-project survey).

Project Lessons:

The Tajikistan case shows that a consistent and coordinated ACSM programme conducted through a national strategy that is informed by a baseline assessment can make significant inroads in increasing TB knowledge. The project further shows how ACSM efforts have a direct impact on achieving appreciably more effective service delivery, community engagement and patient outreach efforts.

Ukraine

Reducing treatment default through enhanced provider communication skills and improved collaboration between actors

Submitted by: PATH

PATH

PATH works to create sustainable, culturally relevant solutions that enable communities to break longstanding cycles of poor health. PATH has been working in Ukraine to strengthen TB control since 2001. Currently, PATH is being supported by USAID to expand DOTS to 10 priority regions in the country, with the goal of achieving coverage of 50% of the population by 2011. Among the components of the project is a major focus on ACSM techniques.

TB Challenge:

TB is a significant public health problem in Ukraine, with notification rates more than doubling between 1992 and 2006. Exacerbating the situation and of serious concern are remarkably high rates of drug resistance and the rapidly growing HIV epidemic. The number of new cases of HIV infection in 2006 increased by 16.8% over the 2005 level, with 2007 seeing 10% growth (UNAIDS Country Progress Report 2008).

The situation is exacerbated by weak coordination between HIV and TB service structures, which significantly hampers caregivers' efforts to effectively deliver services to vulnerable populations, as well as by the high stigma faced by TB and HIV patients within both the health care system and society at large. This stigmatization contributes to extremely high default rates, which considerably exceed 20% in some oblasts (regions).

ACSM Intervention:

In addition to improving the quality of DOTS, the project worked to establish a patient-oriented approach to providing TB and TB/HIV services among the most vulnerable groups. This intervention and a communications programme to counter a persistent anti-TB stigma amongst health workers were identified during a previously-applied assessment as likely high-impact activities in the strategic effort to improve patients' adherence to treatment.

A major end-goal of improved DOTS implementation was to decrease default rates in those oblasts where the treatment completion levels are the lowest. ACSM is an important element of the effort, and is a critical part of several project components, notably including those that enhance support to patients. Especially prominent have been efforts to provide greater support to patients from disadvantaged groups, which post the highest levels of treatment default.

Project activities were informed by several types of baseline assessments (e.g. a KAP survey, focus groups and in-depth interviews). These diagnostic exercises aimed to: determine client satisfaction with current TB services; assess clinician perspectives on the reasons behind the country's high default rates; determine the main reasons why certain populations delay seeking treatment or have difficulty completing the course of treatment; and gather opinions of both patients and clinicians on what they think could help patients adhere to treatment regimens.

About one-third of clients sampled were either dissatisfied or very dissatisfied with their interaction with providers, and nearly 70% were dissatisfied or very dissatisfied with their provider's willingness or ability to explain treatment options. Nearly 90% of respondents indicated that no written information on TB or TB treatment was provided.

To correct this situation, PATH worked intensively with local partner Ukraine Red Cross Society (URCS), training its coordinators on effective project management, programme implementation and principles of DOTS. Furthermore, all TB facility-based providers were trained in interpersonal communication and counselling, including diagnostic testing and counselling for HIV, while UCRS nursing staff were further trained on DOTS treatment issues. Training also worked on reducing TB stigma and discrimination against TB patients by providers.

In close consultation with URCS and TB facilities, PATH established a system to guide communication and collaboration between and among facilities, patients and visiting nurses. The group also supported URCS efforts to develop linkages and referral mechanisms to assist patients and their families who need social services (which patients often prioritize ahead of TB treatment). This step included help in identifying local funding to support such needs as nutrition, clothing, shelter and transportation.

PATH also subcontracted URCS to carry out collaborative activities with TB medical facilities. The activities aimed to: support treatment completion among patients who choose to receive follow-up TB treatment on an outpatient basis at Red Cross aid stations; work with TB patients who have interrupted their treatment; help provide accurate information about TB and encourage timely consultations with medical providers for local citizens, retirees and municipal services and housing staff.

Both PATH and URCS developed a joint monitoring tool to collect and evaluate the necessary data on patient outcomes.

Project Results:

Although numbers are still small, preliminary cohort data suggests that default rates among TB patients were almost zero in the intervention sites, as compared to 10-20 % in non-intervention sites. The advocacy programme also achieved notable results, including its securing funding from local budgets (oblast level) for continued support of URCS patient assistance programme and a pledge of increased support from medical providers to collaborate with the URCS in its TB programme.

Project Lessons:

A patient-centred approach in TB services – particularly towards vulnerable and at-risk patients – can considerably reduce defaulter rate, especially when activities are undertaken in collaboration with partners who have experience working with and access to the relevant populations. Efforts to make projects sustainable can benefit greatly from an advocacy programme that focuses on creating local networks of support (cash or in-kind) and collaboration with medical providers.

ADVOCACY, COMMUNICATION AND SOCIAL MOBILIZATION FOR TB CONTROL

Collection of country-level good practices

An initiative of the Advocacy, Communication and Social Mobilization Subgroup of the Stop TB Partnership

www.stoptb.org/countries/acsm/

978 92 4 150062 3

Stop TB Partnership

World Health Organization