

**DEVELOPING SOCIAL MOBILIZATION & COMMUNICATION INDICATORS
FOR USE IN TB PROGRAMME MONITORING: A WORKING DOCUMENT**

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Monitoring should primarily serve the needs of the immediate project management, and only secondarily the needs of senior management at the headquarters or the needs of statistical data collection. Unfortunately, this has often not been the case in the past, mainly because monitoring was promoted by the donor agencies as a means of keeping watch on what was happening to 'their' project. So monitoring largely comprised data collection with very little relationship to the on-going needs of management.¹

DRAFT

¹ Cracknell, B.E. (2000) *Evaluating Development Aid: Issues, Problems and Solutions*. P.163. New Delhi: Sage Publications.

INTRODUCTION

TB-DOTS programmes now cover nearly half of the world's population yet only about 30% of people with infectious TB are currently diagnosed and treated under DOTS.² We need to rapidly expand quality DOTS services. At the same time, we need to *stimulate public use of DOTS services* and *ensure that TB patients complete their treatment* to avoid the creation of drug-resistant TB strains. These are two key behavioural goals that can only be achieved through strategically planned and well-executed social mobilization and communication activities. Unfortunately, *DOTS services do not sell themselves*.

A framework of indicators to measure country progress in reaching the targets of 70% case detection rate and 85% cure rate is required not only to assist national TB programmes (NTPs) in their efforts but also to help external agencies understand how best to target technical and financial assistance. During 2002, several agencies worked on standardized indicator sets for TB control. USAID has been collaborating with MEASURE on the development of a set of indicators that would allow the evaluation of USAID-funded TB projects. A draft list of indicators is now available and field tests are in preparation. WHO/STB has worked on a set of indicators for external evaluation of National TB Programs. A draft set of indicators was presented at the STAG meeting in July 2002, and STAG requested STB to finalize the development of indicators in close collaboration with other agencies.

Current indicators used to monitor DOTS programmes focus predominantly on the *managerial and clinical aspects of expanding quality DOTS services* at various levels of a national health system. The indicators generate data in the following nine broad areas: **(a) political commitment** (national policies, guidelines, budgets, etc.); **(b) drugs** (costs of drugs, quality assurance); **(c) TB burden** (various case notification rates, percentages of new TB cases, etc.); **(d) diagnosis** (number of active TB-diagnostic centres per population, case detection rates, proportion of laboratories with functioning equipment, etc.); **(e) treatment** (% of new smear positive cases cured, etc.); **(f) management** (% utilization of TB budgetline, proportion of regular supervision visits actually conducted, average percentage of stock out for TB drugs, etc.); **(g) training** (e.g., national plan includes training plan, training materials, etc.); **(h) supervision** (national checklist, etc.); and **(i) recording/reporting** (% of units submitting complete and timely reports, proportion of units receiving feedback on reports, etc.).³

While these indicator sets are important for measuring progress towards and maintenance of quality DOTS services, we need additional indicators that can help TB programmes and collaborative agencies *understand why so many TB sufferers are not entering DOTS services and in some situations, not completing treatment, and then take necessary action to address these problems*.⁴ Very few of the above indicator sets will provide this type of information.

The purpose of this working document is to present and discuss five key sets of indicators to monitor progress made by national TB programmes towards two key behavioural goals – *stimulating use of DOTS services* and *assuring treatment compliance*:

² DOTS stands for Directly Observed Treatment Short-course. The DOTS strategy comprises five elements: political commitment and resources, microscopy, treatment, medicines, and monitoring.

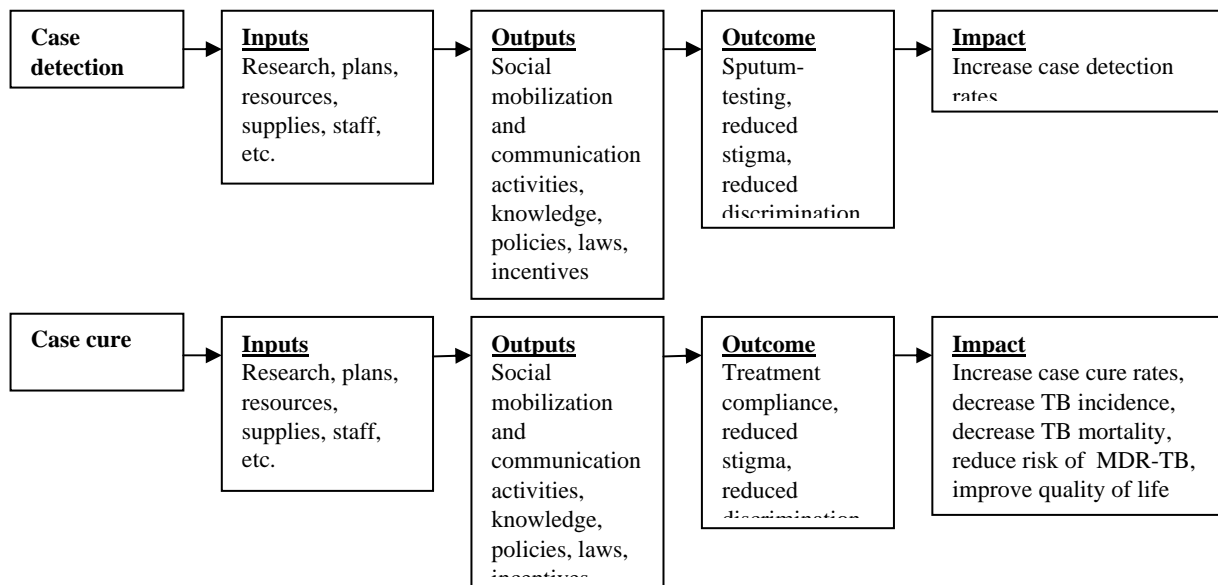
³ This list of nine areas was generated by combining the WHO and USAID indicator lists presented at the TB M&E meeting in Geneva, 18th December 2002. The USAID indicator list also proposed indicators for TB/HIV, Information-Education-Communication, MDR-TB programs, prison programs, public-private mix, socio-economic support, infection control, operational research. At the time of writing, these indicator sets were under discussion.

⁴ The main obstacles for achievement of high case detection rates and high cure rates may be poor quality DOTS services, preference for alternative therapies (both non-medical and through private physicians), economics, lack of information, social stigma and discrimination, or various combinations of these obstacles.

- (a) **social mobilization and communication capacity** (*input* indicators)
- (b) **social mobilization and communication activity** (*output* indicators)
- (c) **sputum-testing** (*outcome* indicators)
- (d) **treatment compliance** (*output* and *outcome* indicators)
- (e) **stigma and discrimination** (*output* and *outcome* indicators).

A framework for how these indicator sets link to programme goals is displayed below.

Framework for monitoring and evaluating social mobilization and communication contributions to DOTS expansion.⁵



The first indicator set relates to programme *capacity* to design, implement and evaluate strategic social mobilization and communication plans that stimulate use of DOTS services and assure treatment compliance (the two key behavioural goals). As such, this indicator set can be considered indicative of DOTS service *inputs* in terms of research, planning, staff, supplies, and resources required to design, implement and evaluate social mobilization and communication activities.

The second set of indicators relate to the delivery of these inputs in terms of social mobilization and communication *activities* or *outputs*. These outputs would generally fall under the following five key action areas:

- *Public Relations/Advocacy/Administrative Mobilization*: for putting sputum-testing and DOTS treatment compliance on the public and administrative/programme management agenda via the mass media – news coverage, talk shows, soap operas, celebrity spokespersons, discussion programmes; meetings/discussions with various categories of government and community leadership, service providers, administrators, private physicians; official memoranda; partnership meetings.

⁵ Adapted from UNAIDS (2000) *National AIDS Programmes: A guide to monitoring and evaluation*. Geneva: UNAIDS/00.17E.

- *Community Mobilization*: including use of participatory research, group meetings, partnership sessions, school activities, traditional media, music, song and dance, road shows, community drama, leaflets, posters, pamphlets, videos, home visits.
- *Sustained Appropriate Advertising*: in M-RIP fashion – Massive, Repetitive, Intense, Persistent, via radio, television, newspapers and other available media, engaging people in reviewing the merits of the recommended behaviour vis-à-vis “cost” of carrying it out.
- *Personal Selling/Interpersonal Communication/Counselling*: involving volunteers, school children, social development workers, other field staff, at the community level, in homes and particularly at service points, with appropriate informational literature and additional incentives, and allowing for careful listening to people’s concerns and addressing them.
- *Point-of-Service Promotion*: emphasizing easily accessible and readily available sputum-testing and effective treatment.

Outputs of social mobilization and communication would also include knowledge and attitudinal change. These, of course, can be measured using population-based surveys (e.g., % of population who are aware of at least 2 symptoms of TB, % of population who know that TB is a curable disease, % of population who understand the link between TB and HIV, etc.).⁶ These output indicators can determine the extent to which key messages have reached the general population or the specific sub-population being surveyed. They are not however reliable nor particularly useful measures of behavioural outcomes (e.g., sputum-testing, treatment compliance, fewer discriminatory actions). Knowledge does not necessarily reflect behaviour. Along the way one does need to increase knowledge but an informed and educated public is not necessarily a behaviourally responsive public. This working document emphasizes the need to measure *behavioural outcomes* not knowledge outputs. Hence the proposal to focus measurement on actual social mobilization and communication activities conducted by TB programmes rather than solely on knowledge or attitudinal change. Some knowledge indicators are proposed and relate to knowledge that a chronic cough (coughing for 3 weeks) could be a sign of TB, knowledge that sputum-testing is the best way to diagnosis TB, knowledge that sputum-testing is free at DOTS facilities, knowledge of nearest location for free sputum-testing, knowledge that TB is curable, and knowledge that TB-treatment through DOTS is free.

The next two indicator sets (sputum-testing and treatment compliance) relate directly to the two key behavioural *goals* that social mobilization and communication for TB control should aim to achieve. In the case of treatment compliance, “incentives” given to patients or a patient’s family (e.g., donated gifts, free food, small financial investments that accrue interest during the time a patient is on treatment, etc.) to encourage poor or marginalized populations to complete treatment are examples of possible *outputs* of social mobilization and communication (e.g., persuading private business to donate gifts, arranging for local community groups to provide regular meals for patients, etc.). At the same time, one could consider incentives as a form of *input* if they are viewed as “resources” a programme provides (but without well-planned social mobilization and communication, these resources could not be generated in the first place – a “chicken and the egg” problem which I would not worry about in terms of labelling incentives as an input or output. The essential point is the need to recognize incentives as assisting treatment compliance).⁷

The final set of indicators relates to a cross-cutting sociocultural barrier that in many countries diminishes efforts to reduce TB morbidity and mortality: namely, stigma and discrimination. This indicator set covers both *outputs* of social mobilization and communication (e.g., anti-

⁶ Taken from USAID’s proposed indicator list presented in Geneva, 18/12/02.

⁷ Small incentives could also be organized to encourage sputum-testing as has been proposed in social mobilization and communication for behavioural impact (COMBI) plans in Kenya, India (Kerala State) and Bangladesh.

discrimination workplace legislation) and *outcomes* (e.g., reduced discrimination against TB-positive patients in workplace settings).

The last three indicator sets (sputum-testing, treatment compliance, stigma and discrimination) are linked to the first two indicator sets: social mobilization and communication capacity and activity. TB programmes need to have well-planned social mobilization and communication activities and must have the resources to conduct these activities if they are to increase case detection and case cure rates through DOTS services.

Each indicator set is described in the context of the two main NTP goals: 70% TB case detection and 85% TB case cure. For most indicators, the data requirements are summarized, and reference is made to the instruments required or tool kits already available. These indicators could be included in comprehensive monitoring and evaluation guidelines which could also strengthen in-country monitoring systems. The document begins with a brief synopsis of considerations in proposing these five sets of indicators.

Documents reviewed:

- Aggleton, P. and Parker, R. (2002) *World AIDS Campaign 2002-2003. A conceptual framework and basis for action: HIV/AIDS stigma and discrimination*. Geneva: UNAIDS/02.43E.
- UNAIDS (2000) *National AIDS Programmes: A guide to monitoring and evaluation*. Geneva: UNAIDS/00.17E.
- Pinet, G. (2001) *Good practice in legislation and regulations for TB Control: An Indicator of Political Will*. Geneva: Stop TB, WHO. WHO/CDS/TB/2001.290. http://www.who.int/gtb/publications/General/TB_2001_290legisl.pdf
- Summary of Discussions of the STOP-TB Virtual Forum on the subject of: Progress made since the Amsterdam Declaration. <http://www.comminit.com/st2001/sld-3396.html>.
- Evaluation indicators. <http://www.comminit.com/evalindicators/sld-2380.html>
- International Center for Research on Women (2002) *Understanding HIV-related Stigma and Resulting Discrimination in Sub-Saharan Africa*. Research Update, June.
- Stop TB (2002) *Advocacy and Communications Assessment of the 22 High Burden Countries*. Geneva: Stop TB Partnership. Draft report.
- USAID draft indicators for Tuberculosis (as presented at Geneva on 18/12/02).
- WHO draft indicators for Tuberculosis (as presented at Geneva on 18/12/02).
- Cracknell, B.E. (2000) *Evaluating Development Aid: Issues, Problems and Solutions*. New Delhi: Sage Publications.

BASIC CONSIDERATIONS WHEN DEVELOPING INDICATORS TO MONITOR SOCIAL MOBILIZATION AND COMMUNICATION FOR TB CONTROL

The primary task of monitoring should always be to provide management with a constant flow of decision-oriented information. The following considerations were used when developing the indicators described in this document:

- Indicators should accurately reflect the objectives of DOTS expansion.
- Indicators should be verifiable, reliable, relevant, sensitive, specific, cost-effective, and timely.
- Indicators need not be “quantifiable” – this is often impossible and even undesirable if the effect of quantification is to put the spotlight on what may be in fact relatively unimportant aspects, for example, the number of people trained on a course rather than the quality of the training. This has been called the “irony of measurement”, that is all too often we measure the *relatively* important things because the *really* important ones cannot be measured. Rather than straining for quantification, it is often better to use qualitative indicators which may be mainly descriptive, or which may depend on an opinion given by someone well qualified to judge.⁸
- Indicators can involve costly data collection, therefore it is essential to be very selective and only choose those that are likely to shed real light on NTP progress.
- In choosing indicators, regardless of level (input, output, outcome, impact), it seems important to limit their number to a set of critical indicators. A multitude of indicators creates difficulties of interpretation and inability to focus on essentials.
- Two important criteria emerge for choosing indicators: a) degree of measurability and b) the cost of obtaining and processing data.
- It is also important to choose indicators where it is possible to establish trends rather than viewing isolated data.
- There is a need to strike a balance between indicators that are close to the activity level (thus many and specific) and those that are further away (fewer and more general).
- The choice of appropriate indicators will vary according to the goals of each TB programme, which will in turn be determined by the stage of the TB epidemic, availability of human and other resources, existing health infrastructure, the prevalence of HIV and MDR-TB, the degree of mobilization of health personnel and the community, the programme’s current progress, and the social context (e.g., TB is widely stigmatized). For example, areas with high cure rates but low case detection rates will be interested most in improving indicators relating to sputum-testing; areas with high detection rates but low cure rates will be interested most in improving indicators relating to treatment compliance; areas with both low detection and cure rates will be interested in improving indicators relating both sputum-testing and treatment compliance; and so on.
- The indicators apply to both government and non-government managed TB programmes.
- **Periodicity** by which these indicators should be used is NOT discussed in this working document at this point in time.

⁸ Cracknell, B.E. (2000) *Evaluating Development Aid: Issues, Problems and Solutions*. Pp.110-111. New Delhi: Sage Publications.

**INDICATOR SET A:
SOCIAL MOBILIZATION AND COMMUNICATION CAPACITY**

The control and prevention of tuberculosis (TB) depends ultimately on the behavioural responses of a broad range of individuals and institutions at the country-level, ranging from behaviours of individuals affected by or at risk of TB to the behaviours of a host of others: community leaders, government officials, politicians, policy makers, government health care providers, private physicians, and middle management administrators in health systems. While many factors contribute to behavioural outcomes, **they simply cannot be achieved without structured and strategically planned social mobilization and communication support for specific and precise behavioural results.**

Capacity to conduct social mobilization and communication activities depends upon a variety of interrelated factors including: (a) having designated managerial staff with appropriate qualifications and experience; (b) having access to appropriate agencies from which technical advice can be regularly sought and to which specialized work can sub-contracted; (c) having a well-researched, strategic plan with a precise behavioural goal by which activities can be properly coordinated, monitored and evaluated; and (d) sufficient human and financial resources to implement planned activities.

The following indicators are proposed to measure programme *capacity* to design, implement and evaluate social mobilization and communication for behavioural impact.

INDICATOR SET A: SOCIAL MOBILIZATION AND COMMUNICATION CAPACITY

No.	Indicator	Calculation	Level	Means of collection
1	% of districts/provinces with designated social mobilization and communication staff with appropriate experience ^λ	Numerator: # of districts/provinces with designated staff for social mobilization and communication Denominator: Total # of districts/ provincial TB control units *	Provincial District	Interview with sample of Provincial and District TB managers
2	Designated national TB social mobilization and communication manager with appropriate experience	Yes/No	NTP	Interview NTP manager
3	% of districts/provinces with access to social mobilization and communication staff with appropriate experience	Numerator: # of districts/provinces with access to staff for social mobilization and communication Denominator: Total # of districts/provincial TB control units	Provincial District	Interview with sample of Provincial and District TB managers
4	Access at national level to social mobilization and communication staff with appropriate experience	Yes/No	NTP	Interview NTP manager
5	% of districts/provinces with <i>written</i> social mobilization and communication plan with clearly stated behavioural goals ^φ	Numerator: # of districts/provinces with social mobilization and communication plan Denominator: Total # of districts/provincial TB units	Provincial District	Interview with sample of Provincial and District TB managers
6	<i>Written</i> national TB social mobilization and communication plan with clearly stated behavioural goals	Yes/No	NTP	Interview NTP manager
7	% of district/provincial plans derived from an in-depth understanding (e.g., via situation market analysis, needs assessment, qualitative research) of current behaviours and actions needed to promote desired behaviours	Numerator: # of districts/provinces with research-based social mobilization and communication plan Denominator: Total # of districts/provincial TB units	Provincial District	Interview with sample of Provincial and District TB managers
8	National level provides guidelines, training, supervision and funding to encourage sub-national planning and implementation of social mobilization and communication	Yes/No	NTP	Interview NTP manager

^λ *Appropriate qualifications* refers to a set of criteria such as: tertiary level health communications training, field experience in managing communications programmes, and so on.

* Definition of *unit* will depend on country context. Could be individual health centres, clusters of health centres, TB control teams spread out across several centres, and so on.

^φ *Behavioural goal* refers to a specific, measurable, appropriate, realistic and timebound statement such as: “To prompt, over the period of a year, approximately 500,000 individuals (men, women and children of any age) throughout Bangladesh (but particularly those in rural areas) who have a cough that does not go away after three weeks to come/be taken to one of the 500 designated government health facilities for The Free TB (Sputum) Test.” Statements referring to “raising awareness” or “changing knowledge” or “increasing community participation” are **not** precise behavioural goals.

INDICATOR SET A: SOCIAL MOBILIZATION AND COMMUNICATION CAPACITY (continued)

No.	Indicator	Calculation	Level	Means of collection
9	100% of all relevant levels have active inter-agency committees or teams contributing to the planning and management of social mobilization and communication ^α	Numerator: # of districts/ provinces with active inter-agency committees contributing to the planning and management of social mobilization and communication Denominator: Total # of districts/provincial TB units	Provincial District	Interview with sample of Provincial and District TB managers
10	National social mobilization plan derived from an in-depth understanding of current behaviours and actions needed to promote desired behaviours	Yes/No	NTP	Interview NTP manager
11	% of district/provincial units that have detailed operational plans for social mobilization as well as more general plans ^π	Numerator: # of districts/provinces with detailed operational social mobilization and communication plan Denominator: Total # of districts/provincial TB units	Provincial District	Interview with sample of Provincial and District TB managers
12	National programme has detailed operational plan for social mobilization as well as more general plan (if necessary)	Yes/No	NTP	Interview NTP manager
13	% of district/provincial units that regularly review, monitor and update social mobilization and communication plans	Numerator: # of districts/provinces conducting regular reviews of social mobilization and communication plan Denominator: Total # of districts/provincial TB units	Provincial District	Interview with sample of Provincial and District TB managers
14	National programme regularly reviews, monitors and updates the national social mobilization and communication plan	Yes/No	NTP	Interview NTP manager
15	% of all relevant levels with sufficient trained communication personnel to conduct planned activities ^β	Numerator: # of districts/ provinces with sufficient training communication personnel Denominator: Total # of districts/provincial TB units	Provincial District	Interview with sample of Provincial and District TB managers
16	% of all relevant levels with sufficient communication materials to conduct planned activities	Numerator: # of districts/ provinces with sufficient communication materials Denominator: Total # of districts/provincial TB units	Provincial District	Interview with sample of Provincial and District TB managers
17	% of all relevant levels with sufficient funding to conduct planned activities	Numerator: # of districts/ provinces with sufficient funding for social mobilization and communication activities Denominator: Total # of districts/provincial TB units	Provincial District	Interview with sample of Provincial and District TB managers

^α Active would need to be defined.

^π Operational plans detail specific activities, responsibilities, completion/implementation dates, and budget.

^β Sufficient would need to be defined. Primary health care workers should receive basic training in TB control such as how to recognize the symptoms of TB and refer suspected patients for accurate diagnosis and treatment. In many countries, community leaders and volunteers can also be successfully involved in TB control. Communities can encourage TB patients to go for sputum-testing and to complete treatment.

INDICATOR SET B: SOCIAL MOBILIZATION AND COMMUNICATION ACTIVITY

This second set of indicators measures the delivery of the above inputs in terms of social mobilization and communication *activities* or *outputs*. As noted above, these activities would generally fall under the following five key action areas:

- *Public Relations/Advocacy/Administrative Mobilization*: for putting sputum-testing and DOTS treatment compliance on the public and administrative/programme management agenda via the mass media – news coverage, talk shows, soap operas, celebrity spokespersons, discussion programmes; meetings/discussions with various categories of government and community leadership, service providers, administrators, private physicians; official memoranda; partnership meetings.
- *Community Mobilization*: including use of participatory research, group meetings, partnership sessions, school activities, traditional media, music, song and dance, road shows, community drama, leaflets, posters, pamphlets, videos, home visits.
- *Sustained Appropriate Advertising*: in M-RIP fashion – Massive, Repetitive, Intense, Persistent, via radio, television, newspapers and other available media, engaging people in reviewing the merits of the recommended behaviour vis-à-vis “cost” of carrying it out.
- *Personal Selling/Interpersonal Communication/Counselling*: involving volunteers, school children, social development workers, other field staff, at the community level, in homes and particularly at service points, with appropriate informational literature and additional incentives, and allowing for careful listening to people’s concerns and addressing them.
- *Point-of-Service Promotion*: emphasizing easily accessible and readily available sputum-testing and effective treatment.

A key indicator for external agencies would be that the NTP and relevant levels of the programme have established a system by which implementation of these activities are being monitored, data are collated, and feedback provided as, when, and where necessary. Some essential instruments and activities that could be used as criteria by which to assess such a system are described below.

National Programmes would need to establish a process evaluation system to adequately track actual implementation and compare it to planned implementation. Process evaluation is based on such questions as:

- Is the activity reaching the people for whom it was designed?
- What do the participants think of the activity?
- Is the activity being implemented as planned?
- Are all aspects of the activity of good quality?
- What kind of participation is occurring?
- To what extent is the direction of the activity changing in response to the needs of the participants?

Process evaluation is often fragmented because data are collected separately – often using different methods – for each activity. Ideally, process evaluation should bring together implementation data from all activities, providing NTPs with an overall picture of their social mobilization and communication plan’s achievements and recommendations for further improvement. Common process evaluation instruments and activities include:

Bounceback cards – short questionnaires on the back of a stamped, addressed post card (addressed to the NTP headquarters or lead agency managing the social mobilization and communication – hence the name). These cards can be included with any materials (e.g., posters, videos, pamphlets) distributed to target audiences, intermediaries (e.g., clinics, schools)

or partner agencies (e.g., TV stations). A few questions can be written on the back of the card to assess such issues as reactions to the materials or provide information on how to order more copies. Bounceback cards often have a low response rate but for programmes covering large geographic areas, such cards often provide the only tracking data on material distribution.

Inventory tracking – apart from ensuring that an adequate stock of various materials/products is always available, inventory tracking offers the chance to learn where materials/products are going, when they were dispatched, which audiences or groups are being reached, which ones are the most or least popular (which are always requested, which are never requested and why), and so on. Plotting the number of requests by date and comparing this with specific social mobilization and communication activities gives an insight into what activities generated the most requests. Less popular activities (generating fewer requests) can also be examined to determine whether they can be improved. Mapping geographic distribution of requests can also indicate areas where requests were fewer and could be targeted with more intensive social mobilization and communication.

<p>An inventory tracking database includes:</p> <ul style="list-style-type: none"> • Date of distribution • Name of material/product distributed • Quantity • Geographic location • Group, Organization distributed to

Service delivery – monitoring delivery of technical services and activities (e.g., diagnosis, treatment) is essential. Specific service delivery data needed to track progress will depend on the NTP’s behavioural goals, but in general, service delivery data includes:

- number of people presenting for sputum-testing;
- peak usage times (to assess staffing and adjust if necessary); and
- additional services of interest to clientele (to make future refinements).

Client satisfaction – ascertaining client satisfaction with the service/s, the facilities, and the personnel is as important as assessing service delivery. Data can be obtained through:

- unsolicited client responses (e.g., “suggestion” or “comment boxes” placed at points of service, but remember potential biases – those who leave comments may have very different views from those who don’t leave comments);
- observation and interviews (e.g., a manager visits a DOTS facility or accompanies a team of volunteers on their household visits and chats with clients about their opinions and suggestions on the service or activity); and
- meetings (not on a specific issue), focus groups (focused on specific issues) and formal, in-depth interviews with householders, neighbourhood committees, business managers, government officials, environmental groups, etc.;
- surveys of representative samples of target segments and/or programme partners using questionnaires.

Tracking surveys – Alongside measuring actual behavioural impact, a good monitoring system will be able to track the extent to which target segments have been reached by social mobilization and communication activities, their understanding of key messages, how their behaviour has changed and why, and if not, why not. Closely linked to client satisfaction, tracking surveys are used to assess comprehension of communication actions and to determine target audiences’ current behaviours and motivations to change.

Media coverage analysis – Tracking and analyzing both the amount and content of media coverage (all mentions of a topic such as “free sputum-testing” that appear as something other than an advertisement on TV, radio, or in newsprint) can help determine:

- how many opportunities there were for people to be exposed to stories or articles containing information about a particular topic;

- identify which messages are appearing in the media (with what frequency, through which media) and which are not, allowing assessment of how TB is framed from a policy perspective and offering insight into how future content of media outreach might be tailored (remembering that mass media such as TV, radio and newsprint often reach and influence key decision makers).

Monitoring policy changes – Monitoring policy changes depends on what type of change it is and at what level of society the power to change policy resides. For example, if businesses are asked to make changes (such as developing anti-discrimination policies) then information needs to be gathered (through interviews, letters, phone calls, etc.) from their public relations officer or relevant manager. If an NTP is trying to gauge whether provincial governments have made legislative changes to laws forbidding discrimination against TB-positive people, then attendance at appropriate government meetings or maintaining contact with key officials will be important.

“Knowledge change” is also an *output* of social mobilization and communication. Knowledge indicators such as % of population who are aware of at least 2 symptoms of TB, % of population who know that TB is a curable disease, % of population who understand the link between TB and HIV, are useful measures of the *reach* of a social mobilization and communication programme’s messages among the general population. They are not, however, reliable or useful indicators of healthy behaviour. The following knowledge indicators could be proposed as output indicators of social mobilization and communication as they closely relate to the two behavioural goals: knowledge that a chronic cough (coughing for 3 weeks) could be a sign of TB; knowledge that sputum-testing is the best way to diagnosis TB; knowledge that sputum-testing is free at DOTS facilities; knowledge of nearest location for free sputum-testing; knowledge that TB is curable; and knowledge that TB-treatment through DOTS is free.

INDICATOR SET B: SOCIAL MOBILIZATION AND COMMUNICATION ACTIVITY

No.	Indicator	Calculation	Level	Means of collection
1	% of districts/provinces with established and active monitoring system for social mobilization and communication activities	Numerator: # of districts/provinces with established and active monitoring for social mobilization and communication activities Denominator: Total # of districts/ provincial TB control units	Provincial District	Interview with sample of Provincial and District TB managers
2	% of population who are aware that a chronic cough (coughing for 3 weeks) could be a sign of TB	Numerator: # of people who correctly identify cough that last for 3 weeks as possible sign of TB Denominator: Total # of people surveyed	Population	DHS TB Module ???
3	% of population who know that sputum-testing is the best way to diagnosis TB	Numerator: # of people who correctly answer that sputum-testing is the best way to diagnosis TB Denominator: Total # of people surveyed	Population	DHS TB Module ???
4	% of population who know that sputum-testing is free at DOTS facilities	Numerator: # of people who correctly answer that sputum-testing is free at DOTS facilities Denominator: Total # of people surveyed	Population	DHS TB Module ???
5	% of population who know the location of their nearest sputum-testing facility	Numerator: # of people who correctly name the location of their nearest sputum-testing facility Denominator: Total # of people surveyed	Population	DHS TB Module ???
6	% of population who know that TB is curable	Numerator: # of people who correctly answer that TB is a curable disease Denominator: Total # of people surveyed	Population	DHS TB Module ???
7	% of population who know that TB-treatment through DOTS is free	Numerator: # of people who correctly answer that TB-treatment through DOTS is free Denominator: Total # of people surveyed	Population	DHS TB Module ???

INDICATOR SET C: SPUTUM-TESTING

A suitable combination of indicators already proposed by USAID and WHO for smear diagnosis can be used to measure the behavioural outcome of social mobilization and communication activities in terms of people presenting themselves or family members for sputum-testing. From a social mobilization and communication standpoint (as opposed to a clinical standpoint), behavioural impact is simply the measure of the numbers of people who present at DOTS facilities *requesting* the TB Sputum Test. Whether they receive the test or not, and whether the test is accurate or not is **not** a social mobilization and communication issue and requires other indicators!

NTPs could develop their own measures for monitoring behavioural impact. For example, an NTP could establish a base-line measure of the current number of people coming in for the test at a random sample of “sentinel clinics” in the three month period before a social mobilization and communication programme is implemented. The NTP could then monitor the numbers presenting at these sentinel clinics during a defined period (e.g., 1 year) and a final comparative figure can be arrived at the end of the year. The NTP could issue interim reports at 4 months and 8 months into the social mobilization and communication programme.

INDICATOR SET D: TREATMENT COMPLIANCE

A suitable combination of indicators already proposed by USAID and WHO for DOTS (e.g., % of new smear-positive cases cured (cure rate), % of new smear-positive cases who completed treatment (completion rate), proportion of all cases under DOTS following DOT as described in national guidelines, etc.) can be used to measure the behavioural outcome of social mobilization and communication activities in terms of TB-patients complying with treatment. Monitoring smear-conversion from positive to negative smear after the initial two to three months of treatment is the most effective way to assess that the patient has taken prescribed medications. Indicators that provide relevant data on a sample of treatment “drop-outs” at various levels of the health system (those who are diagnosed smear positive but do not commence treatment or those who are diagnosed smear positive, commence treatment, but do not complete) needs to be considered (e.g., % of new smear positive cases who default, % of new smear positive cases who were transferred to another district, etc.).⁹

This indicator set should also contain an indicator or indicators that measure the establishment and implementation of pro-poor incentive schemes to encourage treatment compliance. For example, **% of districts/provinces that have active pro-poor incentive schemes for TB-patients on DOTS.**

INDICATOR SET E: STIGMA AND DISCRIMINATION

Stigma has been defined as ‘an attribute that is significantly discrediting’ and ‘an attribute used to set the affected person or groups apart from the normalized social order, and this separation implies a devaluation’. Stigmatization therefore describes the process of devaluation within a

⁹ Taken from USAID’s proposed indicator list presented in Geneva, 18/12/02.

particular culture or setting, where certain attributes are seized upon and defined as discreditable or not worthy.

In the case of TB, stigma may be applied to actual infection or to behaviours believed to lead to infection (e.g., connection with HIV/AIDS transmission). Stigma plays into, and reinforces, existing social inequalities, being linked to power and domination in the community as a whole. It should be noted however, that the concept of stigma may be unclear or differ in particular societies or languages.

Stigma is harmful, both in itself, since it can lead to feelings of shame, guilt and isolation of people living with TB, and also because negative thoughts often lead individuals to do things, or omit to do things, that harm others or deny them services or entitlements (i.e., discrimination). Discrimination is essentially the different, and most commonly negative, treatment of an individual or group of individuals because of one or more factors attributed to them. Stigma and discrimination are intimately linked; stigmatization often leads to discrimination, and discrimination can take many forms.

Discrimination can exist at many levels. Hospital or prison staff, for example, may deny health services to a person living with TB. Or employers may terminate a worker's employment on the grounds of his or her actual or presumed TB-positive status. Families and communities may reject and ostracize those living, or believed to be living, with TB. Such acts constitute discrimination based on presumed or actual TB-positive status and violate human rights.

Stigma and discrimination associated with TB are among the greatest barriers to preventing further infections, providing adequate care, support, and treatment and alleviating impact. TB-related stigma and discrimination are universal, occurring in every country and region of the world. They are triggered by many forces, including lack of understanding of the disease, myths about how TB is transmitted, prejudice, lack of access to diagnosis and treatment, irresponsible media reporting, the link between HIV/AIDS and TB, and fears relating to illness and death. Evidence from country studies also reveal that the rights and choices of TB-positive women are repeatedly ignored or denied, that the policy framework to support their rights is weak and that their needs are almost always secondary to those of others in the community.

Lack of access to TB diagnosis and treatment is a key issue that enhances or advances TB-related stigma and discrimination in many countries. The perceived 'untreatability' of TB is a key factor contributing to the stigmatization of many of those affected. As long as TB continues to be equated with serious illness and death, public attitudes towards the epidemic seem likely to be slow to change. For this reason, *the efforts being made to expand DOTS services should help to reduce stigma and discrimination and indicators used to measure the progress towards DOTS expansion can act as proxies for reductions in stigma and discrimination.*

Nevertheless, strengthening the legal framework to protect the human rights of people with TB (and HIV/AIDS) is also seen as paramount. A human rights framework provides avenues for people who suffer discrimination on the basis of their actual or presumed TB-positive status to have recourse through procedural, institutional and monitoring mechanisms. At national level, these include courts of law, national human rights commission, ombudsmen, law commissions and other administrative tribunals. **Input/output indicators measuring the establishment of these legal institutions could be developed.** Simultaneously, communities need to be empowered to understand and use policy and the law to obtain the care and support they require. **Outcome indicators measuring use of these legal institutions could be considered.**

Policy and legal reform, however, will have limited impact unless supported by values and expectations of a society as a whole. Widespread and enduring changes in social attitudes are required if we are to make headway against TB-related stigma and discrimination. It is thus considered vital to create supportive environments to reduce TB-related stigma through national and community-based social mobilization and communication initiatives to combat fear and misinformation and to increase use of DOTS services. Various indicators proposed in Indicator Set B could be used to measure implementation of social mobilization and communication initiatives directly addressing stigma and discrimination. In addition, indicators could be developed to measure the extent to which social mobilization and communication plans and activities address topics such as TB/HIV, discrimination against female patients, and the professional conduct of private physicians, government health workers, prison staff, and employers.

Indicators to consider in this set might include:

- % of people expressing accepting attitudes towards people with TB, of all people surveyed aged 15-49. This could be based on hypothetical questions about men and women with TB – it reflects what people are prepared to say they feel or would do when confronted with various situations involving people with TB.
- % of formal-sector employers sampled with non-discriminatory policies and non-discriminatory practices in recruitment, advancements and benefits for employees with TB. The indicator should be disaggregated to look separately at company policies and practices.
- % of district/provinces that have established the legal framework to protect the human rights of people with TB.
- % of district/provinces that organize communication activities (e.g., training programmes) to empower communities to understand and use policy and the law to obtain the care and support they require for TB patients.
- % of district/provinces that can show evidence of enforcing current legislation against mandatory TB-testing and testing without consent.
- % of districts/provinces that have set in place codes of ethics and professional conduct for health workers (both government and private) such as confidentiality and mechanisms for their effective implementation at all levels.
- % of national/provincial/district level health worker training curricula that teach codes of ethics and professional conduct as they relate to TB (and HIV/AIDS).
- % of district/provinces providing training and support for existing legal aid institutions, alongside creation of lawyers' collectives specializing in TB-related concerns.