LIGHTS OF HOPE

A National Communication Strategy for Fighting Tuberculosis in Kenya

October 2005

USAID FROM THE AMERICAN PEOPLE

MINISTRY OF HEALTH

PATH
A catalyst for global health

This publication was made possible through support provided by the Kenya Mission under Kenya MAARD No. 615-003-3-40021 through the U.S. Agency for International Development, under the terms of Contract No. GHS-I-01-03-00034-00. The opinions expressed herein are those of the author(s) and do not necessarily reflect the views of the U.S. Agency for International Development.

Lights of Hope

A National Communication Strategy for Fighting Tuberculosis in Kenya

October 2005

USAID FROM THE AMERICAN PEOPLE
MINISTRY OF HEALTH
PATH A catalyst for global health

CONTENTS

ABBREVIATIONS

AIDS.....Acquired Immune Deficiency Syndrome
BCC.....Behavior Change Communications
CBO .....Community Based Organisation
CHW.....Clinical Health Worker
DO .....District Officer
DOT(S) .....Direct Observed Treatment (Short- course)
DTLC.....District Tuberculosis and Leprosy Coordinator
HIV .....Human Immuno-deficiency Virus
IEC .....Information Education and Communication
IMPACT.....Implementing HIV & AIDS Care Project
NACC.....National AIDS Control Council
NASCOP.....National Aids and STI Coordination Program
NGO .....Non Governmental Organisation
NLTP.....National Leprosy & Tuberculosis Programme
PLWHA.....Person Living With HIV or AIDS
PLWA.....Person Living With AIDS
PHC .....Primary Health Care
PHO.....Public Health Officer
PHT .....Public Health Technicians
STI .....Sexually Transmitted Infection
TB .....Tuberculosis
TBA.....Traditional Birth Attendant
UCLA .....University of California, Los Angeles
VCT.....Voluntary Counseling and Testing

PREFACE

Tuberculosis has regained its footing in Kenya at a time when people have all but abandoned hope because of the AIDS epidemic. The timing could not be worse; the need for urgent action could not be greater.

Tuberculosis once used to be a "social" disease, complicated by isolation, fear, and stigmatization. The advent of modern treatment and cure did much to erode these attitudes and fears, and tuberculosis began to be seen as a condition that did not mean the end of life and lifestyle. But the ground gained in the fight against tuberculosis is now in danger of being lost again as the disease re-awakens in the shadow of a much more daunting epidemic: AIDS.

In poverty-ridden settings, tuberculosis is among the leading causes of death among people with AIDS. Not surprisingly, many see it as a telltale sign of HIV infection or AIDS. The tuberculosis cough is itself hard to conceal—if left untreated, it worsens into a wracking, prolonged coughing fit that robs its victim of sleep and makes it impossible to eat, drink, and perform most normal activities. It must seem the cruellest irony that AIDS, a condition that is desperately denied and hidden, is announced in many cases by something so difficult to ignore.

Amidst the general confusion that surrounds these two linked but separate conditions, people may have forgotten that tuberculosis infection does not signify HIV infection, or that while AIDS inevitably leads to death, tuberculosis is curable, regardless of whether a person has HIV infection. But even if this information were to be clearly and urgently delivered, it might not prove sufficient, especially for those who believe that one disease will inadvertently reveal another that they would rather not know about. Many people insist that knowing one has HIV infection actually hastens death, and they use this reasoning to avoid going for voluntary counselling and testing.

Communicating for change of health-seeking behaviour with regard to tuberculosis in today's Kenya is complicated by these factors. Simple information would barely begin to turn the tide, unless attended by innovative strategies to reach families and give them the knowledge and courage to step out of their cloisters and choose prompt and appropriate treatment that will save lives.

EXECUTIVE SUMMARY

The links between advocacy, communication, and social mobilization

Lights of Hope describes a standalone National Tuberculosis Communication Strategy for use in Kenya in the fight against tuberculosis (TB). It is based on a study of health-seeking behaviours among Kenyans, strategy design workshops with stakeholders, and meetings with frontline TB workers. Its goal is to present a strategy for reducing the impact of TB in Kenya through communication strategies aimed at behaviour change.

It is worth noting, however, that poor health-seeking behaviour among those infected with the TB bacillus is only part of the picture. The fight to stop TB in Kenya requires concerted action, steeled by political will and financial commitment, at the highest levels of the land to address policy, human resources, and financial gaps. These are outside the purview of a National Tuberculosis Communication Strategy.

To be effective, the National Tuberculosis Communication Strategy must work in close coordination and synergy with the National Tuberculosis Advocacy Strategy. Ongoing consultations, as well as a task force to continuously review progress and to identify weaknesses, opportunities, and emerging linkages between the two strategies are important.

Social mobilisation priorities and needs will emerge at different stages during the implementation of the communication and advocacy strategies. The planning, design, and execution would fall to those agencies, nongovernmental organisations, and individuals charged with implementing projects within the strategies.

Three stages of TB infection

The nature of behaviour change involved in dealing with TB differs sharply from that associated with the AIDS epidemic. Coping with AIDS calls for a deep-seated, consistent, committed change of attitudes and behaviour that is tantamount to a change in lifestyle. Coping with TB calls for a specific action of limited duration. Once the bacillus has been purged from the body, the need for behaviour change ends. The required actions are: promptly seeking diagnosis when a cough is persistent and, once the treatment is underway, adhering to the treatment regimen.

The preliminary research that led to this strategy document revealed three distinct stages in the progression of infection within an individual: Pre-Diagnosis, Post-Diagnosis, and Treatment. At each stage, the wrong decision can lead to death. Each stage has its own psychosocial characteristics. In terms of a communication strategy, each stage also has unique primary and secondary audiences, capacity-building requirements, intervention strategies, appropriate media, outputs, and outcomes. These insights profoundly influence the National Tuberculosis Communication Strategy and the associated messaging framework, choice of media, and communication approaches.

Pillars of the National Tuberculosis Communication Strategy

The National Tuberculosis Communication Strategy in Kenya is built on three pillars:

- Provoking enquiry
- Demonstrating hope and options
- Empowering families and individuals to act

These pillars are the philosophical foundation on which the rest of the communication strategy is built. They are derived from insights that emerged from research data and other evidence and are worded to provide broad guidance and emphases for anyone else developing a communication plan for TB in Kenya.

Communication objectives, audiences, and media

Objectives

The objectives of the National Tuberculosis Communication Strategy are:

1. To create a clear understanding in the general population that TB is curable if it is diagnosed and treated early, regardless of HIV status.
2. To build the capacity of frontline health workers and other caregivers to thoroughly understand the clinical manifestations of TB, HIV, and AIDS and to deliver care and treatment with a positive attitude, hope, and compassion.
3. To create understanding of the warning symptoms of TB and the consequences of delay in seeking diagnosis at a recommended health facility.
4. To create confidence that government health facilities can diagnose, treat, and cure TB at no cost in most cases that are reported early.
5. To increase the involvement of the family and the community in ensuring adherence to TB treatment regimens.

Audiences

Achieving these objectives means reaching both primary and secondary audiences (table 1). The family unit has been identified as an important primary audience for TB communication, because its role spans all three stages of TB infection (Pre-Diagnosis, Post-Diagnosis, and Treatment). However, the family is also a generic and hard-to-reach audience, especially in the Pre-Diagnosis stage when they are invisible to the medical system. Reaching the family before diagnosis requires the identification of alternative audiences that provide indirect access to the family. Such audiences include:

- Men at worksites
- Women at worksites
- Couples at health care settings
- School-going youth
- Caregivers of people living with HIV/AIDS
- People living with HIV/AIDS
- Frontline health workers
- Traditional birth attendants
- Herbalists/traditional healers
- Voluntary councelling and testing counsellors

Secondary audiences, chosen because they have the ability to influence the community or are gatekeepers of access to primary audiences, include:

- Elders and chiefs
- Religious leaders
- Teachers
- Employee unions
- Families at TB clinics
- Nongovernmental or community-based organizations

Table 1. Audiences matched to communication objectives of the National Tuberculosis Communication Strategy during different stages of tuberculosis (TB).

	Audiences	
Infection stage	Primary	Secondary
	Objective 1. To create a clear understanding in the general population that TB is curable if it is diagnosed and treated early, regardless of HIV status.	
Pre-Diagnosis	Men at worksites, women at worksites, couples at health care settings, school-going youth, caregivers of PLHA, PLHA, frontline health workers, TBAs, herbalists/traditional healers, chemists	Elders, chiefs, religious leaders, teachers, employee unions
Post-Diagnosis	Men at worksites, women at worksites, couples at health care settings, families at TB clinics, school-going youth, caregivers of PLHA, PLHA, frontline health workers	Elders, chiefs, religious leaders, teachers, employee unions
	Objective 2. To build the capacity of frontline health workers and other caregivers to thoroughly understand the clinical manifestations of TB, HIV, and AIDS and to deliver care and treatment with a positive attitude, hope, and compassion.	
Pre-Diagnosis	Frontline health workers, chemists, herbalists/traditional healers, VCT counsellors	
Post-Diagnosis	Frontline health workers, chemists	
Treatment	Frontline health workers, chemists	
	Objective 3. To create understanding of the warning symptoms of TB and the consequences of delay in seeking diagnosis at a recommended health facility.	
Pre-Diagnosis	Men at worksites, women at worksites, couples at health care settings, school-going youth, caregivers of PLHA, PLHA, frontline health workers, TBAs, herbalists/traditional healers, VCT counsellors, chemists	Elders, chiefs, religious leaders, teachers, employee unions
	Objective 4. To create confidence that government health facilities can diagnose, treat, and cure TB at no cost in most cases that are reported early.	
Pre-Diagnosis	Men at worksites, women at worksites, couples at health care settings, school-going youth, caregivers of PLHA, PLHA, herbalists/traditional healers, VCT counsellors, chemists	Elders, chiefs, religious leaders, teachers, employee unions
Post-Diagnosis	Men at worksites, women at worksites, couples at health care settings, school-going youth, caregivers of PLHA, PLHA, herbalists, chemists	Elders, chiefs, religious leaders, teachers, employee unions
	Objective 5. To increase the involvement of the family and the community in ensuring adherence to TB treatment regimen.	
Treatment	Men at worksites, women at worksites, couples at health care settings, school-going youth, caregivers of PLHA, PLHA, frontline health workers, NGOs/CBOs	Elders, chiefs, religious leaders, teachers, employee unions

Note: CBO, community-based organisation; NGO, nongovernmental organisation; PLHA, people living with HIV/AIDS; TBAs, traditional birth attendants; VCT, voluntary counselling and testing.

Media

The choice of media is based on the premise that persuasive information and individual and community endorsements are the most powerful tools for encouraging health-seeking behaviour to reduce the impact of TB. The communication strategy proposes deployment of interlinked mass media, mid-media, and traditional media to achieve results.

Mass media

- Radio
- Print
- Television

Mid-media

- Closed-circuit TV in hospitals
- Posters
- Pamphlets
- Booklets
- Testimonials

Traditional media

- Community theatre
- Puppets
- Song

METHODS

This communication strategy is the final product of a process that included a behavioural study conducted in July 2000; two stakeholder strategy design workshops, in Mombasa and Kakamega, in February 2001; and a consultative meeting with frontline TB workers in June 2005. The findings and insights gleaned from these processes guided the formation of this strategy.

Behavioural study (July 2000)

The research design for the behavioural study was completed in July 2000, and the fieldwork was conducted in August. The principal objectives were:

1. To identify popular conceptions about and descriptions of TB and TB symptoms.
2. To explore patterns of use of alternative therapy options in the study communities.
3. To identify psychosocial and structural barriers to care.
4. To examine clinic-level factors that affect the diagnostic and treatment process.
5. To examine issues of stigma associated with TB and HIV.

Methods included semi-structured interviews with patients at TB clinics, structured interviews with individuals from the general population, direct observation of patient-provider interactions, and loosely structured interviews with health providers and officials working in TB services in Kenya.

The findings from interviews with patients and individuals from the general population were on the whole very consistent, revealing key themes present in the larger study populations, and were consistent with the issues raised during community stakeholder strategy design workshops. These workshops, together with the consultative meeting with frontline workers drew out additional issues that were addressed in the communication strategy.

Interviews with TB patients

A qualitative assessment of important issues and concerns was derived from semi-structured interviews with 36 patients conducted during the formative assessment. Patients described the onset of their symptoms, their initial treatment action, their first contact with a professional health care provider, and the point at which TB was diagnosed. Patients were asked to describe the different therapies they tried before first contact with the formal biomedical sector and their experience with the biomedical sector itself. A series of questions was devoted to patients' social support with regard to seeking treatment and to their experience with stigma related to TB.

Interviews with individuals from the general population

A total of 447 respondents from Kakamega, Bungoma, and Busia in Western province and Mombasa in Coast province were identified through door-to-door household interviewing, using a quota sampling method with predetermined age and sex categories that reflected population statistics. The study instrument used both open- and closed-ended questions to measure

common perceptions about coughs and related diseases; basic knowledge about TB symptoms, cause, transmission, and treatment; and popular notions about the relationship between TB and HIV/AIDS and the stigma attached to both diseases.

Limitations

Although substantial qualitative data were used in the analysis, some gaps in information remain. Because the patients interviewed in the behavioural study were already receiving treatment at TB or municipal clinics, we have no direct information about individuals in whom TB had not been diagnosed. In addition, only retrospective information about the early symptoms and treatment-seeking behaviours of the interviewed patients was available, and this is subject to recall bias. However, based on the data, we can make some reasonable and useful inferences about what happens after individuals are infected and before TB is diagnosed.

In addition, some topics were not covered in the behavioural survey. The most important of these topics is adherence; patients' experience with adhering to therapy was not explored. In addition, respondents in the general population survey were not asked directly about the double stigma associated with HIV/AIDS and TB. This emerged as an important issue in the creative workshops and patient interviews, and population-based data on this topic would be helpful.

Larger and more representative samples would have added to the findings. In the behavioural study, although the data from the semi-structured patient interviews is rich, the small number of interviews analyzed (36) was insufficient to test for statistical significance. The participants in the community stakeholder strategy workshops, mostly drawn from NGOs, civil society partners, and personnel from the biomedical sector, may not be representative of the population of the target areas (although the findings from these workshops did not differ significantly from those of the general population survey).

Community stakeholder strategy design workshops (February 2001)

Two 2-day stakeholder strategy design workshops were held, in Kakamega and in Mombasa in February 2001. The workshops were attended by key stakeholders, including representatives from Impact partners; representatives from government health care services, in particular from the National Leprosy and TB Programme (NLTP); and other community members. The workshops included simulation games, role-playing, discussions designed to draw out attitudes and issues associated with TB, and group work to identify target audiences and some of the attitudes, misconceptions, information needs, resources, and problems affecting each target group's ability to change TB-related behaviours. Participants were also asked to recommend interventions, messages, and strategies for reaching each target group.

Draft National Tuberculosis Communication Strategy (2002)

This draft National Tuberculosis Communication Strategy, titled ***Lights of Hope,*** was written on the basis of the steps described above.

Consultative meeting with frontline health workers (2005)

District-level TB coordinators and other clinic-level staff at the NLTP met for a two-day consultation in Nairobi to review the status of TB in Kenya as it has changed in the three years between 2002 and 2005, identify current issues that must be addressed within a communication strategy, and review the draft of the ***Lights of Hope*** communication strategy that had been accepted by the NLTP in 2001. We also explored issues that pertain directly to individual treatment-seeking behaviour associated with coughing and TB infection, as well as insights into attitudes, beliefs, influencers, and media at the ground level.

KEY FINDINGS

The issues and observations gleaned from the behavioural study, the community stakeholder strategy design workshops, and consultations with district-level TB coordinators are summarised below.

Poor understanding and miscommunication

General superficial awareness of TB and its seriousness is widespread in Kenya, but specific knowledge is somewhat lacking about specific symptoms, beyond the persistent cough; the importance of early diagnosis; treatment options; and the potential for cure, even in the presence of HIV. Specifically:

- Persistent myths about TB include that it is hereditary and that TB patients should be isolated, even once they are receiving treatment.
- Some patients believe that TB (and/or AIDS) is a result of witchcraft.
- People are generally unaware that TB treatment is free. Many are also unaware of the real costs of a cure, which include transportation and other expenses, even though the treatment itself may be free.
- English is often the only language used. This makes it difficult for non-English-speaking, and even non-English-reading, groups to be included.
- The system encourages defaulters. For example, being told that your sputum test "shows you are infected" can be disempowering and is more likely to create a defaulter than is hearing that "you have an infection that is probably going to be cured, with your help."

Delay in biomedical diagnosis

Individuals often follow a dangerously lengthy route to biomedical diagnosis and treatment. In the behavioural study, people reported trying multiple home remedies, over-the-counter medicines (especially cough syrups), and herbal or traditional treatments. Some consulted a chemist, traditional healer, or witch doctor or informally asked advice from friends in the biomedical sector. These delays could expose more people in the community to infection and make treatment more difficult.

Causes for delaying biomedical diagnosis included poor information about TB symptoms, curability, and the need for a sputum test or x-ray for proper diagnosis. In some cases, poverty or poor transportation caused the delay. In addition, patients' denial of the seriousness of their symptoms and the stigma associated with TB and with the perceived link with HIV/AIDS hampered effective diagnosis and treatment-seeking.

Importance of family's role

The family is a key influencer in all aspects of diagnosis, treatment, and cure of TB. The family (defined here as including blood relatives cohabiting the same home as the patient, as

well as close associates and friends) emerges as a group of crucial influencers—for better or for worse—of people with a persistent cough. Family members play key roles in diagnosis, treatment, and adherence. In some cases, for example, patients reported that their family's encouragement led them to seek biomedical diagnosis and helped them adhere to the treatment regimen. In others, the family prevented or dissuaded the patient from seeking diagnosis or treatment.

Clearly, the family is also the seat of many of the attitudes, both caring and stigmatizing, associated with TB. Some family members assumed that the person with the cough had not only TB but also AIDS and took steps to isolate and stigmatize that person. In other families, there was an assumption that TB was the result of a curse.

The family can play an important role in convincing the patient to seek diagnosis and adhere to medical treatment. On the other hand, ignorance and misconceptions within the family can greatly hinder the patient's treatment-seeking behaviour and adherence to treatment.

Confusion between TB and AIDS

TB is often seen as a symptom of AIDS, rather than as a separate disease. Results from our general population study suggest that people associate TB with HIV; ***more than half of respondents said that "a lot of" or "all" HIV/AIDS patients have TB.*** This suggests that TB is often misread as a sure indicator of AIDS. A person with a severe cough and weight loss may be "diagnosed" by the family and community as having TB and AIDS. Because of the fatalism associated with AIDS, this leads to a lack of motivation to seek TB treatment (since the patient is perceived to be near death due to AIDS). Family and friends may be reluctant to offer encouragement, money, and other assistance in seeking treatment.

Within the family, fear of such social ostracization may conflict with concern for the patient and the need to find an effective cure. In many families, ignorance may combine with the fear that the community will treat TB as a sign of undisclosed AIDS and stigmatize the whole family. This can conflict with the family's concern for the patient and the need for early biomedical diagnosis.

Stigma at all levels

Stigmatization of individuals infected with HIV is seen from the upper echelons of the Ministry of Health to some of the staff in the health facilities. It may be a barrier within the family and in the biomedical sector. Attitudes that emerged during the community stakeholder strategy design workshops suggested that the family may itself be a source of stigma, and as a result that individuals may be segregated within the household on suspicion of TB, rather than encouraged to seek competent biomedical diagnosis. Similarly, frontline health care workers and chemists may discriminate against TB patients because of fear of infection. These stigmatizing attitudes, magnified because of the association between HIV/AIDS and TB, may keep patients from acknowledging their illness and seeking timely help.

Non-adherence

Non-adherence to treatment regimens remains a serious problem that not only leads to increasing drug resistance but also contributes to TB morbidity. Factors leading to non-adherence include distance to place of treatment; belief that TB has been cured once the symptoms disappear; lack of proper health education; poor drug availability (stock-outs); low-quality service from health providers, including bribes being sought; stigma resulting from the belief that people with TB also have AIDS; cost of transportation; weakness caused by AIDS; and fear of injections (especially among men).

Health workers as sources of misinformation and stigmatization

Frontline health workers can be a source of negative attitudes and/or misperceptions in their communities, even though they may not see the need for additional training or knowledge. Negative attitudes and stigmatization of individuals with TB often reflect pessimism about the outcome of treatment and fear of infection. These doubts and fears can be passed on to patients and affect their treatment-seeking and adherence behaviour. Results from the strategy design workshops and the behavioural study suggest that health care workers at private facilities may not have the knowledge or incentive to properly diagnose and treat TB or to refer individuals to government services for diagnosis or treatment.

It is hard to motivate frontline health workers who are working under difficult conditions. They must cope not only with their own fears and prejudices, but also with the community's attitudes. Under these circumstances, some health workers do not want to treat individuals with TB. This builds mistrust between patients and health workers and decreases confidentiality between patients and health workers. For example, health workers may feel that it is his or her duty to alert family and community members to a new and dangerous infection in their midst, even if it means violating confidentiality.

The consultations with frontline health workers also captured their insights on the use of communication materials in the field (table 2).

Table 2. Observations from health workers on tools used for community education on tuberculosis (TB).

Tool	Weaknesses	Lessons learned
Posters	Dull, improperly designed, and misplaced posters divert attention from TB prevention and control.	Eye-catching posters, with few words, that are well-written and conspicuously situated create awareness (in schools, churches, market centres, etc.).
Pamphlets	Issuing pamphlets without a health talk is not effective.	Distribution of pamphlets after giving a health talk in a baraza, schools, and churches attains a greater impact on TB testing and prevention.
Barazas	If no health personnel are present, the chief or district officer gives the health talk and may impart or reinforce negative attitudes.	Convening chief's barazas periodically (once a month) in every sub-location gives an appropriate venue for TB prevention and control.
Interpersonal communication	Transportation is a barrier because of the lack of bicycles and motorbikes to reach all community households. Poor infrastructure = poor interpersonal communication.	When the public health personnel make routine sanitation home visits (village and urban centres), they normally give health education individually; hence a positive response is expected.
Radio	Radio is not effective when communication is in English and by somebody with whom the community does not identify.	Radio is especially effective when aired in local languages. When health education is given by a doctor in the local language, it reaches more people.
Television	Unclear messages that do not call for immediate action are ineffective.	Testimonies from people who have experienced TB and have been cured can give greater impact.
Video clubs	Videos or messages on TB screened without a health worker (or well-trained person) to explain may result in transference of wrong information or none at all.	Local video clubs attract huge numbers of youth and can be used to pass on TB messages.
Drama clubs (theatre)	Drama clubs often lack proper guidance by a health provider on what messages to convey.	Existing groups (HIV/AIDS) can have a big impact on health education, especially in schools and public barazas and on market days.
District TB days and events	Lack of funds is an obstacle.	TB days and events create opportunities for disseminating information on TB prevention, testing, and control.
Promotional materials	Lack of funds is an obstacle.	Strategically designed materials such as t-shirts with messages on TB, banners, and stickers can have an impact.
Motivation		When transportation is provided to public health personnel and a defaulter-tracing allowance is given, the work is dramatically enhanced.

COMMUNICATION RATIONALE

Differentiating communication at the Pre-Diagnosis, Post-Diagnosis, and Treatment stages

To be effective, communication about TB must happen during all three stages at which an individual must act on his or her own behalf—Pre-Diagnosis, Post-Diagnosis, and Treatment. Wrong decisions at any stage can be fatal, and each phase carries its own communication requirements, audiences, and risk profile.

Pre-Diagnosis stage

At the Pre-Diagnosis stage, the individual is already infected, but TB has not been diagnosed, and the individual is largely invisible to health care services. Our behavioural study showed that the Pre-Diagnosis stage can be long and costly for the patient and family, in terms of resources, psychological stress, and delayed treatment. According to patients who were interviewed, this was a period of wondering what to do, where to go, how much it would cost, what other people would think, and whether they really wanted to know whether they had TB and, in some cases, HIV. For some, time is wasted in experimenting with alternative and sometimes costly therapies. Families and close associates might also be wondering whether the individual suspected of having TB poses a health (or social) risk for them.

During this period, the infected person is essentially "invisible" within the community and is effectively out of reach of communication, or at least can be reached only through proxies, such as other family members. Communication designed to shorten this Pre-Diagnosis stage must "sneak" accurate and empowering information and options into family environments through settings such as worksites, schools, and primary health care facilities (which family members may seek out for other reasons). In addition, it is necessary to inform the community more broadly of the critical early symptoms of TB, the seriousness of these symptoms, the need for a sputum test to correctly diagnose the disease, and the need for prompt and sustained biomedical treatment.

This is also the phase during which the patient may be misled and delayed in diagnosis by those whom he or she consults from the health sector. These frontline health care providers include chemists, herbalists, and clinical health care workers. They represent the first contact between the infected person and the health system. Strategically, including them in communication strategies will increase the chances of early detection by promoting a push for early diagnosis at a biomedical testing facility.

Post-Diagnosis stage

Communication strategies for the Post-Diagnosis stage are directed toward individuals who have sought diagnosis at a recommended health facility and toward the families of these individuals. However, the decision to be tested for TB cannot be equated with the decision to proceed with treatment. A variety of factors, ranging from mistrust of the health care provider

and fears that confidentiality will be violated, to poor understanding of the possibility of cure, to economic and other factors, may impede progress. Clear communication, counselling, and empowering testimonials from those who made correct, life-saving decisions in time (including TB survivors) are of immeasurable value.

An advantage during the Post-Diagnosis stage (and during the Treatment stage) is that the patient is now visible and accessible to the health care system, specifically within the clinic setting. Thus, the biomedical treatment TB facility becomes an important venue for specific communication with the person who has received a diagnosis of TB. Strategically, it is important to be innovative and proactive in improvising media and methods that go well beyond traditional posters and leaflets.

Beyond clinics, broad communication aimed at the general community to create social approval for and pressure to seek prompt diagnosis and treatment continues to be important.

Treatment stage

Problems of adherence typically surface during the Treatment stage, when the patient may stop treatment out of complacency arising from a false and premature sense of having being completely cured, constraints imposed by poverty, or other factors. A significant part of the morbidity associated with TB stems from poor adherence to the treatment regimen. As during the Post-Diagnosis stage, the infected person is now accessible to the health care system, the individual's identity is known, and his or her family and social network may be influenced through communication.

Clarifying the distinction between HIV/AIDS and TB

One reason that TB in Kenya is thriving is the natural human fear of what are believed to be "unpleasant truths." The biggest of these involve HIV and AIDS, of course, and because TB is an AIDS-related disease, the stakes are higher, and the shroud of secrecy intensifies. Everything doubles—stigmatization, misinformation, ignorance, reluctance to seek treatment. TB becomes confused with HIV and AIDS: some people believe that they are indicators of each other, while others believe that one leads to the other. For a Kenyan living in poverty, with fear of social stigmatization and scepticism that TB can be cured at all, and within a family structure that is marked by power and gender imbalances, denial of TB may be the first and easiest option, even when the symptoms have become alarming.

Carefully and consistently clarifying the exact connection between HIV/AIDS and TB is an important communication requirement. The link between the two is undeniable, but poorly understood by many. Communication must be explicit and sensitive, so that the despair and fatalism associated with HIV and AIDS is lessened and not automatically transferred to TB. Communication strategies must emphasize that TB is curable, even in HIV-positive individuals, and underline the fact that AIDS and TB are two separate conditions.

Using the family both as audience and communication channel

Throughout an individual's odyssey from the onset of symptoms through diagnosis and treatment to (in many cases) cure, his or her family members, as well as friends and close associates, play key roles. Interviews with individuals in the behavioural study showed clearly that family members can be sources of advice, information, money or other help to facilitate treatment, and encouragement to seek diagnosis and treatment. Family members can also be purveyors of misinformation, ineffective home remedies, and well-meaning advice that only serves to delay diagnosis. In some cases, the family was the seat of fatalism, stigmatization, and despair—and a barrier to care, as in the case of the woman whose father refused to take her to the hospital because he believed she had AIDS. The impetus to seek treatment can be strongly influenced by the family's attitudes and urgings. During the Post-Diagnosis stage, they could easily fuel the hopelessness and fatalism that could lead to opting out of even seeking treatment.

Whatever their role, positive or negative, family members' true potential emerges when they are "recruited" as the custodians or guardians of the curative process. This was clearly illustrated in the Kakamega stakeholder strategy design workshop; all groups that were asked to devise innovative strategies to ensure treatment-seeking and adherence used the family as "watchdogs."

There is a key role within this communication strategy for the patient's family—meaning his or her immediate family and circle of closest associates. These people can act as a channel to the patient, bringing important information about diagnosis and treatment. The family should also be a target for communication interventions, because their own knowledge and attitudes clearly affect the patient's health-seeking behaviour.

Exploring a role for children as advocates

The woman of the family may be seen as the guardian of the family's health. But the power of the Kenyan female to influence treatment-seeking decisions with regard to infected family members is compromised by the dominance and supremacy of the average Kenyan male within the household. Infected women may also be less likely to have the resources or motivation to seek treatment without their husbands' permission. This can place both infected men and infected women in jeopardy—men, because wives do not have the authority or the confidence to push them toward diagnosis, treatment, and a cure; women, because husbands may not be motivated enough to take them for treatment.

There may to be an opportunity here to harness the motivating and persuasive pressure that the children in the house can bring to bear. The child or youth—threatening no power structure, acceptable to both father and mother, cared for, and listened to—represents a direct channel to the older members of the house. As advocates, they have the ears of the entire family. They can be couriers of new knowledge, provocative questions, stories, examples, and hope into a family that is struggling to balance the need for survival against the desire to avoid social stigma.

This strategy requires collaboration with the national education system, including teachers, to empower the child to bring provocative questions, discussions, and information into family settings as part of the school-parent interaction.

Building hope with real-life stories and testimonials

The credibility and acceptability of correct and comprehensive information is linked to who delivers it. While medical professionals are the obvious choices for clinical information about diagnosis and treatment, they will be not be equally convincing when the issues are emotional and touch chords of fear, fatalism, and stigmatization. Indeed, our behavioural study and the creative workshops showed that even medical workers sometimes hold misconceptions about TB.

The information that TB is not hereditary, for example, is far more persuasive coming from a TB survivor who did not have a family history of TB—and was cured through timely treatment. Similarly, the knowledge that TB can and should be treated, even in the presence of HIV infection, carries more credibility coming from a TB survivor who was also HIV positive. The importance of long-term adherence to the treatment regimen might be more convincing if it were advocated by the head of a family that had played a role in the complete cure of one of its members.

The communication strategy should exploit the power of the endorsement and the personal testimonial, as well as the real-life experience of community members, as an approach to fighting fatalism and hopelessness and creating a realistic and evidence-driven climate, in which cure is not only accepted as possible but is championed by those who have undergone treatment and been cured.

Generating enquiry and coordinating response

It is important to shift away from a "handout-based" communication environment to an "enquiry-based" one. Promoting enquiry is a goal of the communication process, especially in the Pre-Diagnosis stage. As individuals and families feel the courage to ask questions about TB, HIV, and AIDS, mechanisms for receiving their requests need to be active within their communities. The government health facility is an obvious collection point for questions from individuals in the Post-Diagnosis stage and the Treatment stage. For those in the Pre-Diagnosis stage or who are in denial, the act of submitting a question might be their first contact with the health care facility. Similar question collection points could exist in other institutions, such as schools, clubs, women's groups, and organizations for people living with HIV/AIDS (PLHA).

This implies a centralized coordination of information flow, preferably in collaboration with an existing national body, such as the NLTP. Received questions should be analyzed to identify main themes of enquiry, and this should guide the preparation of media content. Table 3 lists possible collection points for questions and channels for disseminating responses and information.

Table 3. Points of contact for gathering questions and disseminating information about tuberculosis.

Point of contact	Channels for disseminating responses
Worksites	Peer education programs; television or radio
Schools	Textbooks; television or radio
Family-planning clinics	Television, radio, posters
STI clinics	Television, radio, posters
VCT centres	Television, radio, posters
Post-test centres	Television, radio, posters
Tuberculosis clinics	Television, radio, posters

Note: STI, sexually transmitted infection; VCT, voluntary counselling and testing.

Fostering intersectoral collaborations to intensify focus on specific audiences

The ***Lights of Hope*** communication strategy recommends an approach that is closer to drip-feed irrigation than to flooding—especially during the Post-Diagnosis and Treatment stages, when the patient is accessible through health care settings. In the Pre-Diagnosis stage, too, the strategy recommends directing highly focused communication in selected settings toward individuals who touch the family directly. Such settings include schools (children and youth), worksites (managers and male and female workers as individual groups), sexually transmitted infection clinics, voluntary counselling and testing centres (men, women, and youth), family-planning clinics (married men and women), post-test clubs (people at risk of or infected by HIV), and health facilities (patients and their families).

In addition to the case made earlier for a central role for the NLTP, there is a strong case for intersectoral collaboration between the NLTP; the Kenyan ministries of education, labor/industry, and health; and the National AIDS Control Council. This would be the best way to use existing infrastructures to optimize reach, spending, and impact.

PILLARS OF THE COMMUNICATION STRATEGY

The behaviour change involved in mitigating TB calls for a specific action of limited duration: the infected person must seek an early and correct diagnosis; if TB is confirmed, he or she must seek treatment and diligently adhere to it for a full eight-month period. Once the bacillus has been completely eliminated from the body, the need for behaviour change ends. In this regard, TB communication is sharply different from HIV prevention communication, which must invoke a sustained, lifetime commitment to safer sex.

With TB, the moment for individual action comes and goes in a span of days or weeks. A successful communication strategy ensures that individuals and their families act swiftly and with commitment during that period.

The communication strategy for combating TB in Kenya in built on three pillars, based on the rationale set out in the preceding section. The rationale evolves directly from the findings of both the behavioural study and the creative stakeholder workshops. These pillars are:

1. Provoking enquiry.
2. Demonstrating hope and options.
3. Empowering families and individuals to act.

Provoking enquiry

In a climate of fear, denial, and secrecy, simply disseminating information about TB is unlikely to save lives. Acknowledging that TB may be curable by itself does not imply that diagnosis and treatment will be sought, because this implies disclosure and possible scandal or social stigma. Disseminated information may be received half-heartedly and not acted on. Communication must therefore not only provide accurate information and messages, but also provoke individuals to ask questions about TB and to air their concerns and doubts.

Creating ownership of information is a key requirement in the Pre-Diagnosis stage, a period characterized by "invisibility," poor receptivity, denial, and fatalism. When the infected person or his or her family begin asking the right questions, they are more likely to confidently seek health care and a complete cure. Giving information in response to queries—rather than without solicitation—creates a greater sense of ownership in the recipient. Thus, a formal approach to harvesting and systematically responding to questions may increase the chances that the communication strategy will be successful.

Demonstrating hope and options

Behaviour change will not arise merely from dissemination of correct information about TB, because such information is often discounted by individuals who are strongly fatalistic about the chance for cure. The climate of denial and fatalism can be alleviated by real-life stories and testimonials from individuals who have dealt with TB swiftly and with courage and have emerged, cured, into a new life—even if they were infected with HIV. Weaving these demon-

strations of individual action into the communication strategy will help, more than anything else, to build an atmosphere in which options are possible and people may confront infection with the confidence that others have already done so.

It is important for Kenyans to know not only that they should seek diagnosis and treatment, but that others have done so successfully. The areas of TB treatment and control in which testimonials play a key role are described in table 4.

Table 4. Communication objectives matched with themes that can be emphasized through testimonials in different stages of tuberculosis (TB).

Infection stage	Communication objectives	Themes
Pre-Diagnosis	• To create a clear understanding in the general population that TB is curable if diagnosed and treated early, regardless of an individual's HIV status. • To create thorough understanding of the warning symptoms of TB and the consequences of delay in seeking diagnosis at a recommended health facility.	• The perils of experimenting with casual or traditional cures. • The risks inherent in delaying or postponing diagnosis. • The importance of going to a recommended and competent health care facility. • The need for the family of the infected person to take the lead in pushing for a correct diagnosis.
Post-Diagnosis	• To create a clear understanding among the general population that TB is curable if treated early, regardless of an individual's HIV status. • To create confidence that government health facilities can diagnose, treat, and cure TB at no cost in most cases that are reported early.	• The risks inherent in not seeking treatment promptly once TB is diagnosed. • What quality of care and treatment to expect at a recommended and competent health care facility. • The need for the family to play a key role in pushing for prompt treatment after a TB diagnosis.
Treatment	• To increase the involvement of the family and TB survivors in ensuring adherence to TB treatment regimens.	• The need for family support to ensure adherence to the full treatment regimen. • The need for prompt diagnosis, prompt treatment after diagnosis, and adherence to the full regimen as the only road to cure.

Demonstrating hope requires, above all, that cases of successful behaviour change be magnified at both national and local levels, through selected media, so that victories in the private fight of families and individuals against TB become matters of community pride. Even in clinics and treatment facilities, it is important that cure and treatment statistics be made visible: a prominent public display board with daily updates on numbers of individuals seeking treatment, the number who adhered and were cured, trends in increased reporting (if any), and the number of individuals who were co-infected with HIV but cured of TB could go a long way toward creating an atmosphere in which new behaviour is possible.

Empowering families and individuals to act

The ***Lights of Hope*** communication strategy sees constructive, informed, and collective action within the Kenyan family unit, including close friends and associates, as key to a successful programme against TB. The family unit functions as the seat of both caring behaviour and stigma. It is here that the impulse for health-seeking behaviour originates or is crushed; it is here that hope or fear is born. The family is a powerful source of correct information and myths or misinformation. Most important, it is with the family that the infected person may be found during the difficult Pre-Diagnosis stage, when she or he is invisible to the health care system, out of reach, and becoming progressively more sick.

The behavioural study indicated that gender power dynamics within many families give male members dominance over female members in making decisions about diagnosis and treatment. An infected woman may be disempowered even in making health decisions that could save her own life. She may also have little influence over the health decisions of infected family members. Moralistic male attitudes toward TB may dictate attitudes toward new information and new behaviour options.

Table 5 describes crucial communication inputs, as well as illustrative media and methods for delivering them, that could help empower individuals with TB and their families to act against TB.

Table 5. Communication needs for reducing the burden of tuberculosis.

Need	Media	Method
Correct information and guidance relevant to the prevailing stage of tuberculosis (i.e., Pre-Diagnosis, Post-Diagnosis, or Treatment).	Mass media (radio, television, print)	Advertisements listing early warning symptoms and possible actions; posters and leaflets listing early symptoms, local clinics, and services.
Strategies and options for health care–seeking behaviour (e.g., where to go for reliable diagnosis and treatment, ways to ensure adherence, how to cope with barriers).	Mid-media (closed-circuit television in clinics, community theatre), Mass media (radio, television, print)	Endorsements and real-life testimonials from cured people; posters; leaflets listing early symptoms, local clinics, and services.
Endorsement and acknowledgement of timely and appropriate action. This is a powerful reinforcing step that helps the family feel good about what they have done for the infected person. To be effective, the endorsement must be public (with the consent of the family) and as widespread as possible.	Traditional media (community theatre, tuberculosis support groups)	Endorsements by community leaders of correct health-seeking behaviour, magnification of success stories through mid-media and mass media.

COMMUNICATION OBJECTIVES

The objectives of this TB communication strategy are:

1. To create a clear understanding in the general population that TB is curable if it is diagnosed and treated early, regardless of HIV status.
2. To build the capacity of frontline health workers and other caregivers to thoroughly understand the clinical manifestations of TB, HIV, and AIDS and to deliver care and treatment with a positive attitude, hope, and compassion.
3. To create understanding of the warning symptoms of TB and the consequences of delay in seeking diagnosis at a recommended health facility.
4. To create confidence that government health facilities can diagnose, treat, and cure TB at no cost in most cases that are reported early.
5. To increase the commitment of the family and community in ensuring adherence to TB treatment regimens.

Objective 1. To create a clear understanding in the general population that TB is curable if it is diagnosed and treated early, regardless of HIV status.

Poor understanding of the differences and the links between TB on the one hand and HIV and AIDS on the other is an important factor in the general atmosphere of secrecy and denial that is engendered by stigma and discrimination. The diagnosis of TB is regarded as a proxy for a diagnosis of HIV infection, or worse, AIDS itself. Conversely, those with HIV infection or AIDS may falsely believe that TB in their case is incurable and therefore avoid diagnosis and treatment.

It is important that all infected individuals and their families understand and believe that:

- The presence of the TB bacillus is not an invariable indication of the presence of the virus that causes AIDS (HIV).
- HIV infection does not mean that a person has AIDS.
- TB disease can occur in HIV-positive and HIV-negative individuals and is curable regardless, in most cases, when it is diagnosed early and treated promptly after diagnosis.

Objective 1 is particularly relevant during the Pre-Diagnosis stage, when a family may suspect that one of its members is infected with TB but still engage in denial. Understanding that TB is curable is key to building confidence: families can prevent the death of a member by supporting those who are suspected of having TB in seeking prompt diagnosis and treatment at a recommended health facility.

Objective 2. To build the capacity of frontline health workers and other caregivers to thoroughly understand the clinical manifestations of TB, HIV, and AIDS and to deliver care and treatment with a positive attitude, hope, and compassion.

Increasing case detection numbers in Kenya requires capacity building through communication at the front line, where the infected person first seeks help. Studies reveal that those who do not seek correct diagnosis at a qualified health care facility will typically seek the help of herbalists, chemists, and local health care providers. Their guidance—or misguidance—plays a large role in the underestimation, misdiagnosis, and mistreatment of TB. Communication can help these frontline health providers understand the clinical manifestations of TB, HIV, and AIDS and enlist their influence in ensuring that those with a persistent cough are directed to the correct facilities for diagnosis.

Stigmatization and discriminatory attitudes that may exist within government and other health care facilities also play a large role in undermining confidence in such facilities and influencing infected people not to seek diagnosis or prompt treatment. Capacity building and training delivered here, to improve the quality of attention, services, and care provided to infected individuals, will go a long way in increasing the numbers of those who seek treatment and adhere to it.

Objective 3. To create understanding of the warning symptoms of TB and the consequences of delay in seeking diagnosis at a recommended health facility.

Objective 1 alone will be inadequate in promoting early health-seeking behaviour, as long as confusion about the early warning symptoms of TB exists. The behavioural study showed that a cough is generally not regarded as serious, and the community stakeholder strategy workshop showed that all coughs tended to be treated the same. It is important that all family members understand when to take a cough seriously and seek prompt diagnosis at a recommended health facility.

It is equally important not only that options be exercised, but that the correct, lifesaving options be exercised. In all too many cases, valuable time is squandered seeking inappropriate diagnosis or treatment—for example, from traditional healers or expensive private clinics. Individuals in families should be left with no doubt about the course of action that is most likely to save an infected person's life.

Communication aimed at meeting this objective should cover:

- The main early warning symptoms of TB (e.g., cough, blood in the sputum).
- Where to go for correct diagnosis and treatment.
- The availability of high-quality, free TB treatment at government health facilities.
- The need for family to support and encourage individuals diagnosed with TB to seek treatment.
- The importance of early diagnosis and treatment as a way of preventing the spread of TB to other family members.

Objective 4. To create confidence that government health facilities can diagnose, treat, and cure TB at no cost in most cases that are reported early.

Low levels of information about and confidence in government health facilities is a reason families will hesitate to encourage treatment-seeking behaviour, even though they may fully understand the correct course of action that will save the life of a family member who is infected with TB. Nevertheless, a Kenyan individual's best and cheapest option for fighting TB lies in these government health facilities, which are committed to dealing with TB and fully equipped to do so.

The driving impetus to seek diagnosis and treatment will be the endorsements of others who have successfully been treated at government health facilities. Creating confidence in these facilities calls for a magnification of successful health-seeking behaviour. However, training for health providers at government health facilities that increases their capacity to correctly inform, build hope, and provide effective treatment is equally important.

Communication aimed at meeting this objective should involve:

- Magnifying cases of successful TB health-seeking behaviour and cures.
- Promoting cooperation between the government health facilities and the families of individuals with TB in ensuring adherence, so that the treatment yields the best possible result.
- Building the capacity of health providers to inform, sustain hope, and provide effective care and treatment to TB patients.

Objective 5. To increase the commitment of the family and community in ensuring adherence to TB treatment regimens.

The ability of the family to support members with TB in adhering to a treatment regimen is linked to the family's belief that a feeling of well-being alone is not a sign that TB has been cured. The understanding that defaulting during TB treatment may lead to death at worst, or to a significantly costlier and more difficult second course of treatment because of the development of drug-resistant bacteria, is key to families' participation in ensuring adherence.

The behavioural study showed that the obstacles to adherence tend to be of three kinds—economic or logistical; clinical or administrative; and motivational. Economic or logistical obstacles include time spent getting to the clinic, unavailability of transportation for reaching the clinic, inadequate health education, and poverty. Clinical and administrative obstacles include unavailability of drugs, the quality of reception at the clinic, and lengthy waiting periods at clinics. The issues here require an administrative, rather than a communications, solution.

Motivational factors need to be addressed through endorsements and discussions. It is important to awaken and harness family-level commitment, enterprise, and participation in a complete cure.

Communication aimed at meeting this objective should promote:

- Propagation of strategies used by different families to ensure adherence.
- Dissemination of clear, problem-solution–type information that prepares families for obstacles to adherence and offers ways to overcome them.
- A thoroughgoing understanding of the much higher cost that a relapse will entail.

AUDIENCES

The family unit has already been identified as an important primary audience for TB communication. However, the family is also a nonspecific and generic audience, beyond simple demographic and psychosocial classification. The primary audiences listed in table 6 have been chosen as effective proxies for the family unit, and communication targeted at them directly reaches the family. The primary audiences identified here also have the characteristic of being geographically discrete, and therefore are amenable to specific programming. Secondary audiences are included either for their ability to influence the community or because they are gatekeepers of access to primary audiences.

Table 6. Primary and secondary audiences for tuberculosis information and messaging.

	Relevance of different messages during the stages of tuberculosis		
Audience	**Pre-Diagnosis**	**Post-Diagnosis**	**Treatment**
Primary			
Men and women at worksites	•	•	•
Couples at health care settings	•	•	•
Youth in school	•		•
Caregivers of people living with HIV/AIDS	•	•	•
People living with HIV/AIDS	•	•	•
Frontline health workers	•	•	•
Traditional birth attendants and clinical health workers	•		•
Individuals in institutions: prisoners, refugees, internally displaced persons, uniformed forces	•	•	•
Out-of-school youth	•		•
Secondary			
Elders and chiefs	•		•
Religious leaders	•		
Teachers	•	•	•
Employee unions	•		
Clients at tuberculosis facilities			
Public health officers and public health technicians	•	•	•
Nongovernmental/community-based organizations	•	•	•
Employers	•		•

A rationale for some of these audiences is presented below.

Primary audiences

Men at worksites, women at worksites

In addition to being a major catchment of heads and members of families, men at worksites and women at worksites in industries with poor working conditions represent significant TB risk. This audience also includes men and women who have a higher risk of TB because of HIV infection. The workplace is accessible to a variety of media and messages that can help increase information, understanding, and hope, in both the Pre-Diagnosis and the Treatment stages of TB.

Worksite managers are a special population whose low level of knowledge and understanding of TB aggravates the epidemic. Often, a worker may postpone seeking treatment or even fail to adhere to the regimen because he or she will lose wages for the time spent visiting a clinic. Improved understanding will put managers in a position to formulate more supportive policies in the workplace. This makes them an important group for advocacy. Their improved understanding of the facts, particularly the knowledge that a person who is receiving treatment is no longer infectious, could go a long way toward lessening stigma and improving the working conditions of people with TB.

Couples at health care settings

Married couples, who provide gateways into families, may be reached through a number of health care settings where they seek services unrelated to TB. These include services related to family planning, sexually transmitted infections, voluntary counselling and testing, and primary health care for themselves or an ailing family member. There are two factors that make them appropriate as a proxy audience for reaching families: first, they may live with a TB-infected person; second, while they are waiting at health facilities, they are an ideal and captive audience. Such individuals and health care settings represent powerful ways to reach into families during the Pre-Diagnosis stage.

Youth in school

Children and youth in school represent a powerful proxy audience for carrying TB-related communication and discussions to the family. To be effective as advocates in the fight against TB, they need curricular and extracurricular information and messages that equip them with messages and goals to bring to their families.

Working effectively with child advocates will require collaboration between the NLTP and the Ministry of Education to integrate TB discussions into school curricula. Training teachers and gaining their voluntary involvement and leadership in a child-to-family TB advocacy programme are essential steps in ensuring the full engagement of youth in school.

Caregivers of PLHA

Caregivers of PLHA are generally members of family units and usually women. They may be face to face with the twin realities of AIDS and AIDS-related TB. They also have a vested interest in finding a solution that can save the life of a family member. This group has not only a strong need for information, options, and strategies for coping with sickness and deteriorating health, but also the will to implement those strategies. Arming caregivers with specific knowledge and skills for communicating with other family members and participating in decisions about health-seeking behaviour is a powerful strategy.

PLHA

PLHA are, as individuals, at added risk for TB and, as groups, powerful potential influencers of many of the prevailing fears and attitudes toward TB, especially its feared links with HIV/AIDS. Those who understand that TB can be cured despite HIV infection and have successfully undergone treatment are powerful examples of treatment-seeking behaviour change, provided they find the courage and confidence to endorse such behaviour and speak out for it.

As a result, PLHA groups are an audience both for advocacy and for generalized information about TB, its symptoms, its diagnosis, and its treatment.

Frontline health workers

The first people that a person with a persistent cough meets within a community are likely to be friendly chemists, herbalists, and others in similar professions. Their competence, level of understanding, and skill in delivering information play an important role in an individual's decision to seek prompt diagnosis or continue with traditional cures or cough syrups.

Frontline health workers have a great need for a clearer understanding of TB and are an important target group for training, communication, and capacity-building activities. Their information needs run from the Pre-Diagnosis stage to the Treatment stage.

Traditional birth attendants and clinical health workers

Traditional birth attendants and clinical health workers are trusted community representatives who are regarded as trained and knowledgeable on health matters. In many families, the traditional birth attendant is seen as an advisor with expertise on a range of trivial health issues, in addition to birth and child health. Because the early cough of TB may seem to be a minor issue, a traditional birth attendant's advice may be sought. Her ability to understand the early warning symptoms of TB and correctly guide the patient are important in influencing health-seeking decisions during the early stages of TB.

Secondary audiences

Elders and chiefs

As gatekeepers to the community, elders and chiefs are important advocacy targets who can send signals to families that facilitate changes in attitudes and behaviours. To be effective, they must be familiar with TB and with strategic communication objectives, audiences, and approaches.

Religious leaders

This audience can play a powerful role in destigmatizing TB and helping distance the disease from the negative associations it carries because of its perceived link with HIV. They can also help promote appropriate health-seeking behaviour by promoting a shift away from traditional cures and self-prescription and toward the use of recommended government health facilities. Religious leaders also are unique in their access to and influence over entire families in the community. To be effective, they should be engaged in a well-conceived advocacy plan and receive training to give them some level of familiarity with the symptoms, diagnosis, and treatment of TB.

Teachers

Teachers are a channel for bringing discussions of TB into the classroom, as a way of helping schoolchildren carry them back to their families. They can also assist in supervision and treatment support of colleagues and children. To be effective, they require familiarity with the communication programme's strategic objectives, behaviour change approaches, and their own role in promoting child advocacy.

Table 7 matches the primary and secondary audiences described above with the strategic communication objectives in effect during different stages of infection.

Table 7. Audiences matched to communication objectives of the National Tuberculosis Communication Strategy during different stages of TB appropriate audiences for the five Lights of Hope communication objectives.

	Audiences	
Infection stage	Primary	Secondary
	Objective 1. To create a clear understanding in the general population that TB is curable if it is diagnosed and treated early, regardless of HIV status.	
Pre-Diagnosis	Men at worksites, women at worksites, couples at health care settings, school-going youth, caregivers of PLHA, PLHA, frontline health workers, TBAs, herbalists/traditional healers, chemists	Elders, chiefs, religious leaders, teachers, employee unions
Post-Diagnosis	Men at worksites, women at worksites, couples at health care settings, families at TB clinics, school-going youth, caregivers of PLHA, PLHA, frontline health workers	Elders, chiefs, religious leaders, teachers, employee unions
	Objective 2. To build the capacity of frontline health workers and other caregivers to thoroughly understand the clinical manifestations of TB, HIV, and AIDS and to deliver care and treatment with a positive attitude, hope, and compassion.	
Pre-Diagnosis	Frontline health workers, chemists, herbalists/traditional healers, VCT counsellors	
Post-Diagnosis	Frontline health workers, chemists	
Treatment	Frontline health workers, chemists	
	Objective 3. To create understanding of the warning symptoms of TB and the consequences of delay in seeking diagnosis at a recommended health facility.	
Pre-Diagnosis	Men at worksites, women at worksites, couples at health care settings, school-going youth, caregivers of PLHA, PLHA, frontline health workers, TBAs, herbalists/traditional healers, VCT counsellors, chemists	Elders, chiefs, religious leaders, teachers, employee unions
	Objective 4. To create confidence that government health facilities can diagnose, treat, and cure TB at no cost in most cases that are reported early.	
Pre-Diagnosis	Men at worksites, women at worksites, couples at health care settings, school-going youth, caregivers of PLHA, PLHA, herbalists/traditional healers, VCT counsellors, chemists	Elders, chiefs, religious leaders, teachers, employee unions
Post-Diagnosis	Men at worksites, women at worksites, couples at health care settings, school-going youth, caregivers of PLHA, PLHA, herbalists, chemists	Elders, chiefs, religious leaders, teachers, employee unions
	Objective 5. To increase the involvement of the family and the community in ensuring adherence to TB treatment regimen.	
Treatment	Men at worksites, women at worksites, couples at health care settings, school-going youth, caregivers of PLHA, PLHA, frontline health workers, NGOs/CBOs	Elders, chiefs, religious leaders, teachers, employee unions

MEDIA AND MATERIALS

Strategic guidelines for use of media and materials

Guidelines for use of media and materials were developed on the basis of the initial assessment and the communication strategy described above. Their primary objectives are:

1. To ensure synergy and harmony within all TB communication messages, approaches, and practices within Kenya.
2. To suggest national and regional mechanisms for managing response and disseminating data.
3. To propose strategies for integrating this communication strategy into ongoing and new projects.

Guideline 1. Communication campaigns addressing messaging needs and audiences of the three identified stages of TB progression (i.e., Pre-Diagnosis, Post-Diagnosis, and Treatment) should run concurrently.

At any given moment in Kenya, some individuals will be in the early stages of TB, with a persistent cough; some will have received a diagnosis as sputum-positive at an authorized clinic; and some will be receiving DOTS (directly observed therapy, short course) treatment. It is vital that communication campaigns aimed at these three phases run concurrently and synergistically.

Guideline 2. Management and implementation of advocacy (such as child-to-family advocacy), interpersonal communication, and mass media components should be vested with separate agencies with proven expertise in those areas.

The overall responsibility for coordination of these three diverse functions should be vested with a behaviour change communication implementation task force that includes representatives of the three responsible agencies, as well as representatives of the NLTP, National HIV/AIDS and STD Control Programme (NASCOP), National AIDS Control Council (led by the NLTP), and other stakeholder agencies. Functional leadership of this task force should rest with the NLTP and the agency for interpersonal communications.

Centralized oversight is necessary to ensure that all messages and activities are correctly synchronized and implemented with the greatest efficiency and effectiveness, using available resources optimally and ensuring maximum impact. The reason for vesting central responsibility for this with the NLTP, along with the agency managing interpersonal communication, is that the strategy draws heavily on communities' successes and participation to build ownership and a positive climate of hope. In other words, much of the content may be expected to emerge from community-linked communication activities and then inform both mass media and advocacy components.

Guideline 3. A central response management cell should be created within the NLTP or subcontracted to a Nairobi-based NGO.

A central response management cell is needed to ensure that all comments, feedback, and individual enquiries being generated by the communication campaigns are reviewed and responded to with detailed information, and that management information systems on these responses are systematically shared with the behaviour change communication task force for use within the mass media and interpersonal communication campaigns.

This communication strategy suggests three levels of intervention:

- Individual
- Community
- Facility

An indicator of success would be the quality and level of questions reaching the project from individuals, communities and facilities. A central response management cell would be responsible for ensuring prompt and accurate communication, collation and analysis of quality and content of feedback, and sharing of the analyses with other participating communication partners to inform the development of interventions, messages, and materials for national use.

Guideline 4. The NLTP and the behaviour change communication implementation task force should develop communication and identity guidelines.

The NLTP and the behaviour change communication implementation task force, along with others deemed appropriate by the NLTP, should develop communication standards and identity guidelines in a user-friendly format to help CBOs and NGOs that develop TB-related materials and messages within their projects to maintain consistency with the national identity and content parameters.

Consistent identity and branding of the TB communication programme to maintain harmony between the strategies of independent institutions and those working with the NLTP can be ensured by a single-point guidance on communication and identity standards.

Media selection guidelines

The Kenya National Tuberculosis Communication Strategy is multilayered and nuanced, differentiating between communication needs and audiences at various stages of infection (table 8). These distinctions have implications for media selection at each stage of infection, as well as for the messages and processes relevant to each.

The choice of media below is based on a philosophy of focused targeting of communication efforts, rather than a widespread seeding, to reach specifically designated audiences.

Table 8. Summary of linkages between objectives, audiences, themes, and media for the national tuberculosis communication plan.

Infection stage	Communication objectives	Stage-appropriate themes	Primary audiences	Secondary audiences	Media		
					Mass	Mid	Traditional
Pre-Diagnosis	1, 2, 3	• The perils of experimenting with casual or traditional cures. The risks inherent in delaying or postponing diagnosis. • The importance of going to the recommended and competent health care facility. • The need for the family of the infected person to take the lead in pushing for a correct diagnosis.	Men at worksites, women at worksites, couples at health care settings, school-going youth, caregivers of PLHA, PLHA, frontline health workers, traditional birth attendants/clinical health workers, chemists, herbalists	Elders, chiefs, religious leaders, teachers, employee unions	Radio, print, and television advertisements	Closed-circuit television in clinics, leaflets, posters, child-to-family advocacy, training and workshops for frontline health workers	Community theatre, peer discussion groups, folk media
Post-Diagnosis	1, 2, 4	• The risks inherent in not seeking treatment promptly once TB is diagnosed. • What quality of care and treatment to expect at a recommended and competent health care centre. • The need for the family to play a key role in pushing for prompt treatment after a TB diagnosis.	Men at worksites, women at worksites, couples at health care settings, school-going youth, caregivers of PLHA, PLHA, frontline health workers, traditional birth attendants, herbalists, chemists	Elders, chiefs, religious leaders, teachers, employee unions		Closed-circuit television in clinics, leaflets, posters, child-to-family advocacy, training and workshops for frontline health workers	Community theatre, peer discussion groups
Treatment	2, 5	• The need for family support to ensure adherence to the complete treatment regimen. • The necessity of prompt diagnosis, prompt treatment after diagnosis, and adherence to the full regimen.	Men at worksites, women at worksites, couples at health care settings, school-going youth, caregivers of PLHA, PLHA, frontline health workers, nongovernmental/ community-based organizations	Elders, chiefs, religious leaders, teachers, employee unions	Radio spots, print ads, television spots	Leaflets, posters, child-to-family advocacy, training for frontline health workers	Community theatre

Note: PLHA, people living with HIV/AIDS.

Sample media strategies

Creating a spokesperson family

A major piece of the communication strategy is creating a fictitious spokesperson family, using mass media, mid-media, and traditional media, to represent issues that arise during the Pre-Diagnosis, Post-Diagnosis, and Treatment stages of TB.

An example is the Rahisi family. This imaginary family lives in a fictitious Kenyan town. Family members, through their humorous interactions and conversations among themselves and with their neighbours, friends, doctors, and others in the community, will reflect the range of predicaments related to TB in the age of AIDS. Over the long term, the characters in this family are expected to become culturally popular spokespersons demonstrating the best response to TB infection.

The family includes parents, at least one child younger than 10 years, and two adolescent youth (male and female, between 16 and 24 years). One of them will acquire TB infection. The reactions of the family will exemplify both the thoughtful, questioning approach to health and TB and also irrational, fear-based, ignorant, and life-threatening responses. All exchanges will rely heavily on humour as a vehicle to sustain interest and permit gentle handling of death-related issues.

Communication will consist of capsules with skits not over three minutes long, designed for radio and television, with adaptations into print media and mid-media. Each capsule will explore a single aspect of TB. Clear, accurate information and motivational success stories will form the main content.

Radio spots

Humour- and information-driven radio capsules of approximately three to four minutes will feature the Rahisi family's ongoing experiences with health, TB, and HIV. The launch of the Rahisi capsules should be a well-publicized event. From time to time, promotional schemes and contests could be built into the capsules to build the listenership and promote participation. The Rahisi family spots will address themes relevant to the Pre-Diagnosis and Treatment stages of the progression of TB infection.

Television spots

Humour- and information-driven television spots of approximately one minute will feature the Rahisi family's ongoing experiences with health, TB, and HIV. It is important that television spots not be viewed as health commercials and that in format and style they have the feel of skits. Their punch line should not be a prelude to an advertising message. The Rahisi family television spots will address themes relevant to Pre-Diagnosis and Treatment stages of the progression of TB infection.

Illustrative Rahisi family capsules

These capsules illustrate the humour and content of Rahisi family messaging and how the family can be used to communicate questions and answers about TB.

I'd rather die than wait for a matatu: A funny capsule about two people waiting for a matatu—one to go to his mistress and the other to the clinic for his TB treatment dose. The matatu is late, and the TB patient wants to go home. The philanderer is eager to get to his mistress. The humour hinges on the fact that each is telling the other that what he is doing puts him at risk—of death from TB or HIV infection.

I forgot my pill today: The forgetful father and his assistant at work—today he has forgotten nearly everything he needed. His wallet. His handkerchief. His socks are mismatched. His umbrella is at home. And he has forgotten to bring his TB pills. His assistant lends him money, a handkerchief, a new pair of socks, and a spare umbrella but can't give him his missing TB pills. Just then the man's school-going son runs in with the pills, saying, "Daddy, didn't you forget something important?"

Closed-circuit television in clinics (TBTV)

As part of a collaboration between the Schools of Nursing, Medicine, and Public Health at the University of California, Los Angeles, with WorldSpace and Kenya's Ministry of Health, 1,400 clinics and 74 hospitals in Kenya were identified for implementation of a distance learning initiative for frontline health workers. Satellite information is relayed by WorldSpace directly to receiving terminals (computers, television sets) within clinic and hospital settings. Although primarily intended for frontline health workers, these terminals also represent a precious opportunity to engage patients and their caregivers in waiting rooms in the same clinics.

As part of the Rahisi family strategy, closed-circuit television monitors placed in explicit settings in project areas (voluntary counselling and testing centres, TB clinics, sexually transmitted infection clinics, post-test clubs, family-planning clinics, primary health care centre facilities, worksites, and schools) will continuously play looped tapes to audiences. The content will consist of three- to four-minute capsules, based on the Rahisi family story. Each capsule will illustrate a single point of information, attitude, or action related to TB.

The TBTV strategy will include a strong push for individuals in the different venues to submit questions and give feedback. Distinctive collection boxes should be at hand wherever TBTV is being broadcast. This feedback should be collected and relayed to the collaborating partner who is managing response, such as the NLTP, for processing.

TBTV creates a channel within various settings for reaching families, as well as individuals with TB who are in the Treatment stage. Capsules featuring the Rahisi family will echo characters who may already have been heard on radio and elsewhere within family and workplace settings, with the addition of visuals to the voices. The content of TBTV will emphasize messages related to those in the Treatment stage but also be pertinent to people in the Pre-Diagnosis stage, which might include relatives or friends of people attending the clinic.

Child-to-family advocacy

In this potentially powerful approach, teachers in selected schools work with their classes to increase the students' capacity to understand and respond correctly to TB through specially designed supplementary curricula. Children become "safe" and "non-threatening" channels of communication for carrying dilemmas, predicaments, and communication around TB responses into the family, in the form of schoolwork in which the parents' participation is required.

For example, a child brings home a question, in which he or she has to elicit the family members' responses: "What is the best way to deal with a cough that has lasted three weeks and has now become bloody and productive?" The following week, the child comes home and shares the correct answer with the family.

Magnification of success stories

Individuals and families who consent to telling their stories about working together to cure TB should be prominently magnified in testimonial stories in the editorial section of the press, as well as in radio and television. In the print media, it is expected that these stories should be carried at no cost for their human interest news value and social benefit. Advocacy with the media is a prerequisite for this. Testimonials could also form part of the content of TBTV.

Especially important in this category will be the testimonials of PLHA who are willing to identify themselves and speak out authoritatively and informatively in favour of prompt diagnosis, treatment, and possible cure of TB.

Engaging individuals in clinic settings with innovative materials

All health care settings should be adequately equipped with posters, "frequently asked questions" booklets, TB symptom guides, flyers containing individual endorsements, and real-life success stories of individuals and families who have sought prompt diagnosis and treatment. Posters and other materials could carry visuals that capitalize on the equity of the fictitious spokesperson family, which will have been built up over radio and closed-circuit television.

Specifically, leaflets listing authorized and fully equipped clinics and health care centres where a complete TB diagnosis can be obtained free of cost should be abundantly available.

Reaching the general population through mass media advertising

Key messages pertaining to the Pre-Diagnosis and Treatment stages of TB should form the basis of 30- to 60-second radio and television spots, as well as linked print media messages. Specifically, the advertising should emphasize:

- The difference between TB, HIV, and AIDS.
- The early warning symptoms of TB.
- Endorsements from those who have successfully completed treatment.
- Motivational spots that glorify the role of the family in a complete TB cure.

Mass media publicity should also include a post box number or other address at which audiences can submit their concerns and questions.

Pre-Diagnosis stage

During the Pre-Diagnosis stage, the infection has set in, but there may be denial, ignorance, avoidance, or misguided actions, both at the individual and the family level.

Objective: To ensure that the infected person seeks early diagnosis at an authorized health care centre.

Tone: Motivational, generating confidence in cure, and inspiring speedy action toward early diagnosis.

Content: Specific and accurate information about early symptoms that should be recognized and urgently acted on.

Post-Diagnosis stage

During the Post-Diagnosis stage, the individual has accepted the problem and is more receptive to lifesaving information.

Objective: To ensure that the infected individual takes the decision to seek prompt treatment for TB at an authorized health care centre.

Tone: Clear instruction, informative and specific.

Content: Specific clinical information about treatment requirements; guidance to family members on the importance of losing no time between the TB diagnosis and treatment.

Treatment stage

During the Treatment stage, the emphasis shifts to specific clinic-based information, laid out in portable formats in printed form for use by patients and their families.

Objective: To ensure that the patient with TB who is receiving treatment adheres to the complete regimen of treatment.

Tone: Motivational, informative, generating confidence and knowledge that a cure is possible only if the patient adheres to a complete course, even though he or she may begin feeling "normal."

Content: Specific motivational examples of individuals who found ways to adhere to the complete regimen and were cured. Specific clinical information about the regimen; guidance to family members on the importance of supporting the patient through the period of treatment.

Audiences and key messages for communication objectives

Objective 1. To create a clear understanding in the general population that TB is curable if it is diagnosed and treated early, regardless of HIV status.

Audiences

- Men at worksites
- Women at worksites
- Clients at health care settings
- Clients at TB clinics
- Youth in school
- Caregivers of PLHA
- PLHA
- Frontline health care providers

Key messages

- The biggest difference between HIV and TB is that one of them can be cured.
- If you have a cough that's lasted more than two weeks, go for a TB test immediately.
- Curing TB is a personal choice—even for a person with HIV.
- Early diagnosis, prompt treatment, complete treatment—that's the only way to beat TB.

- HIV doesn't mean TB. And TB doesn't mean HIV.
- Find out what you have. If it's TB, it can be cured. Act fast.
- Once hope replaces fear, TB can be cured.

Objective 2. To build the capacity of frontline health workers and other caregivers to thoroughly understand the clinical manifestations of TB, HIV, and AIDS and to deliver care and treatment with a positive attitude, hope, and compassion.

Audiences

- Frontline health care providers
- Chemists
- Herbalists

Key messages

- You may not have the right cure for TB. But you can always give the right advice.
- Send them now to the nearest government health care facility.
- When they depend on you, don't misinform them.
- Understand TB, don't try to cure it. Send that cough to an approved TB health care facility.
- TB can only be cured at a well-equipped health care facility.
- Don't give out false cures, give out correct advice.
- Caring begins with your eyes.
- Don't look away from TB. It's completely curable. By your advice.

Objective 3. To create understanding of the warning symptoms of TB and the consequences of delay in seeking diagnosis at a recommended health facility.

Audiences

- Men at worksites
- Women at worksites
- Clients at health care settings
- Youth in school
- Caregivers of PLHA

- PLHA
- Frontline health worker
- Traditional birth attendants/clinical health workers
- Chemists
- Herbalists

Key messages

- Persistent cough is a cry for urgent help. Learn to recognize it.
- Let a health care provider at a government health facility listen to that cough. She'll know exactly what to do.
- TB always warns you in time. Act at once.
- Other people have other opinions. You go find out the opinion of the doctor at the government health care centre about that three-week cough. Now.

Objective 4. To create confidence that government health facilities can diagnose, treat, and cure TB at no cost in most cases that are reported early.

Audiences

Primary

- Men at worksites
- Women at worksites
- Clients at health care settings
- Youth in school
- Caregivers of PLHA
- PLHA
- Chemists
- Herbalists
- Traditional birth attendants/clinical health workers

Secondary

- Elders, chiefs
- Religious leaders
- Teachers
- Employee unions

Key messages

- I'm alive today because the government health clinic cured my TB. For free.
- Give them your time, and they'll give you back your life.
- It costs nothing. And it's right around the corner. Why are you hiding at home?

Objective 5. To increase the involvement of the family and the community in ensuring adherence to TB treatment regimens.

Audiences

- Men at worksites
- Women at worksites
- Clients at health care settings
- Youth in school
- Caregivers of PLHA
- PLHA
- Frontline health workers
- NGOs/CBOs

Key messages

- My family refused to let me die.
- I said no. But they all said yes. And I'm alive today.
- The family that lights up hope together, fights off TB together.
- Be your brother's (sister's/father's/mother's) keeper.