



© WHIB/Pierre Viot



# Empowerment and involvement of tuberculosis patients in tuberculosis control:

Documented experiences and interventions

**© World Health Organization 2007**

All rights reserved. Publications of the World Health Organization can be obtained from WHO Press, World Health Organization, 20 Avenue Appia, 1211 Geneva 27, Switzerland (tel.: +41 22 791 3264; fax: +41 22 791 4857; e-mail: [bookorders@who.int](mailto:bookorders@who.int)). Requests for permission to reproduce or translate WHO publications – whether for sale or for noncommercial distribution – should be addressed to WHO Press, at the above address (fax: +41 22 791 4806; e-mail: [permissions@who.int](mailto:permissions@who.int)).

The designations employed and the presentation of the material in this publication do not imply the expression of any opinion whatsoever on the part of the World Health Organization concerning the legal status of any country, territory, city or area or of its authorities, or concerning the delimitation of its frontiers or boundaries. Dotted lines on maps represent approximate border lines for which there may not yet be full agreement.

The mention of specific companies or of certain manufacturers' products does not imply that they are endorsed or recommended by the World Health Organization in preference to others of a similar nature that are not mentioned. Errors and omissions excepted, the names of proprietary products are distinguished by initial capital letters.

All reasonable precautions have been taken by the World Health Organization to verify the information contained in this publication. However, the published material is being distributed without warranty of any kind, either expressed or implied. The responsibility for the interpretation and use of the material lies with the reader. In no event shall the World Health Organization be liable for damages arising from its use.

Printed in France

WHO/HTM/STB/2007.39

# Empowerment and involvement of tuberculosis patients in tuberculosis control:

## Documented experiences and interventions

---

**Jean Macq**

Health Programmes and Policies in Developing Countries Unit, Department of Policy and Health Systems, School of Public Health, Université Libre de Bruxelles, Brussels, Belgium

This publication was commissioned by the Stop TB Partnership and the World Health Organization

February 2007

# Contents

<b>Executive summary</b>	<b>3</b>
<b>Introduction</b>	<b>4</b>
<b>Methods</b>	<b>5</b>
<b>Operational definitions of empowerment and involvement of TB patients</b>	<b>6</b>
Better control by patients of their health and life	6
Peer support	6
Assisting TB control services	7
<b>Barriers to empowering TB patients</b>	<b>8</b>
Barriers to accessing health services	8
Stigmatization and isolation of and discrimination against TB patients	8
'Patient control' in TB programmes	9
Belonging to vulnerable groups	9
<b>Experience with empowerment of TB patients</b>	<b>10</b>
Enabling TB patients to take more responsibility for their health	10
Organization of TB patient groups and clubs	11
Instituting more patient-centred TB and general health care	11
Improving the advocacy skills of TB patients	12
<b>Operationalizing TB patient empowerment: lessons learnt</b>	<b>14</b>
Stakeholders	14
Incentives and enablers	15
Performance of TB control programmes	15
Burden of TB	16
Resource availability and sustainability	16
<b>Scaling-up an experience or intervention</b>	<b>17</b>
Evaluation of the process	19
Outcome evaluation: TB control	19
Outcome evaluation: patient well-being	22
Outcome evaluation: equity	23
<b>Conclusions</b>	<b>24</b>
<b>Recommendations</b>	<b>25</b>
Meaning and purpose of the empowerment of TB patients	25
Barriers to the empowerment of TB patients	25
Design and choice of strategies to enhance the empowerment of TB patients	25
Stakeholders	25
Evaluation and scaling-up	25
<b>Acknowledgements</b>	<b>27</b>
<b>References</b>	<b>28</b>

# Executive summary

Empowering and involving patients with tuberculosis (TB) in the management of their disease is of increasing interest for policy-makers, managers and health care providers involved in TB control. It is clearly connected to other priorities in TB, such as equitable access to services by vulnerable and poor populations, the interaction between TB and HIV, and human rights. It is, however, a complex issue.

This document presents the results of a review of the available published and grey literature on the empowerment and involvement of patients and former patients in TB control. It identifies possible trends and conclusions and suggests ways of informing policy-makers and further research. Multiple strategies were used to ensure that relevant information was used in the review, including key words for the MEDLINE and PSYCINFO databases and use of worldwide web research engines, conference abstracts and project reports.

The review of documented experience covers the means used to enable patients to take more responsibility for their health and, in particular, for adherence to treatment; organizing TB patients into groups and clubs; ensuring patient-centred TB and general health care; and helping TB patients to use advocacy to improve TB control. It describes the operational definitions of and potential barriers to empowerment and the importance of context, including the characteristics of stakeholders, incentives, the performance of TB programmes and the burden of TB. These issues must be explored carefully in evaluating and planning the scaling-up process.

# Introduction

The empowerment of patients in the fight against TB is still an underdeveloped area, although it is not a new concept. For example, in 1992, the United States Centers for Disease Control and Prevention recommended that “Empowerment of at-risk groups in the community is a crucial element in TB control. This step begins with the public awareness campaigns because it is vitally important for members of at-risk populations to understand TB, its impact on the community, how it is diagnosed, treated, and prevented, and what services are available. These populations also should be able to influence TB programs directed toward their communities.” (Centers for Disease Control and Prevention, 1992). In the late 1990s and early 2000s, on the basis of experience with community-based care in Africa and elsewhere, the framework for expansion of the direct observation of treatment strategy (DOTS) included the need for patient-centred care for TB patients (WHO, 2002a). The current Stop TB strategy, which is based largely on DOTS, recognizes empowerment of patients and communities as a key component (Stop TB Partnership & WHO, 2006).

This document presents a review of experiences in empowering patients. Available scientific and descriptive studies on the empowerment of TB patients have been summarized in order to identify and explore possible trends, examine the evidence gap and inform further research. Conclusions have been formulated to assist implementation of this key component of the Stop TB strategy. The document describes successful experiences in empowering and involving TB patients or affected communities in TB control and the delivery of services. The first task was to determine what information was available in the literature on empowering and involving TB patients and former patients in TB control, in particular to analyse any effects on TB programmes and on patient-centred care. The second task was to summarize the available scientific and descriptive studies on the empowerment and involvement of TB patients and former patients in TB control, to identify trends and conclusions and to suggest means for informing policy-makers and further research.

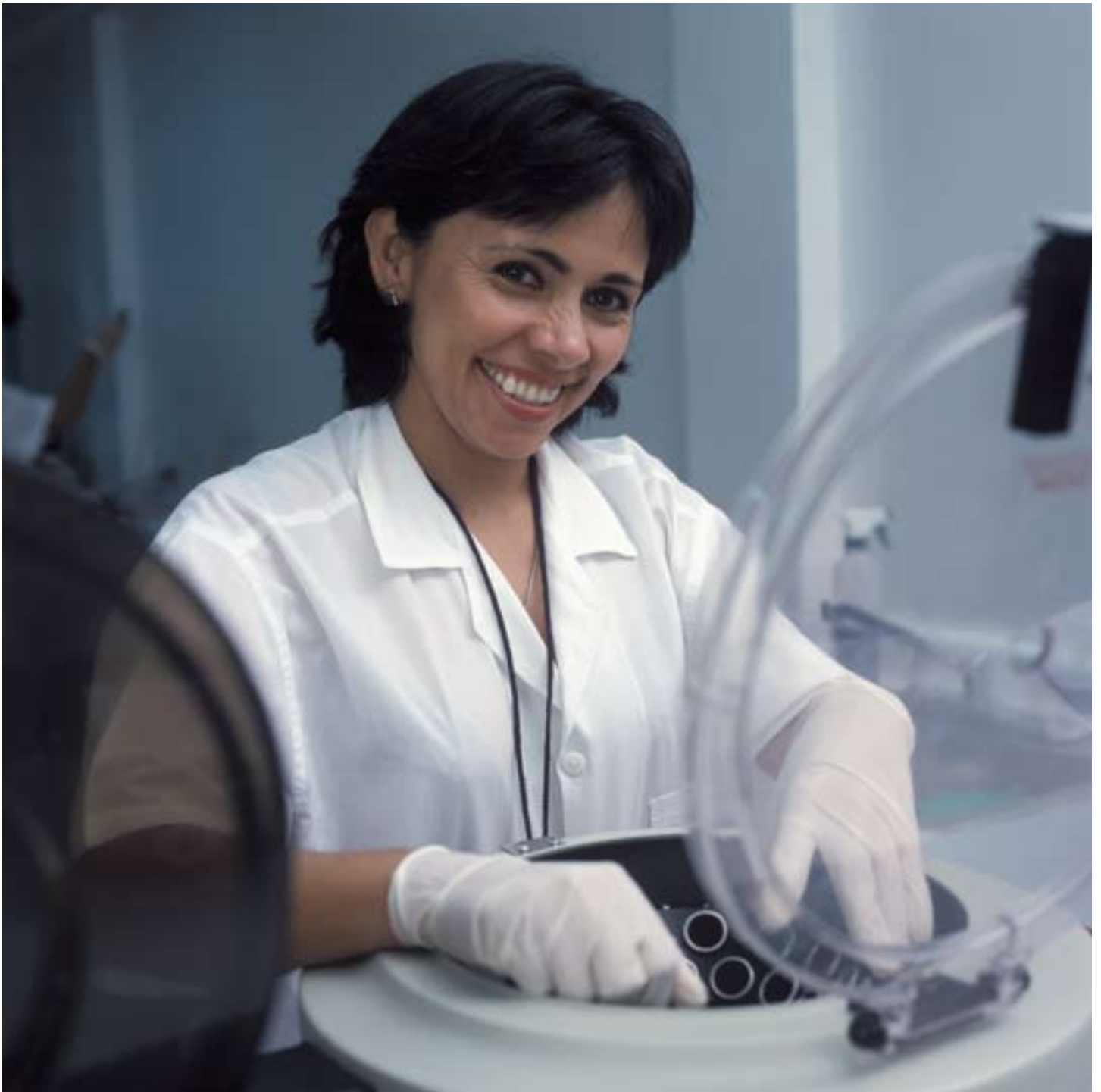
Empowerment and involvement of the patient and patient-centred care in the context of TB control are the central themes of this document. Several reviews on the organization and management of chronic care have explored these relatively vague concepts (Feste & Anderson, 1995; WHO, 2002b; WHO, 2003; Michie, Miles & Weinman, 2003; Hibbard et al, 2004; Mc Gregor, 2006;). The meanings of empowerment and involvement are analysed from the point of view of the conditions necessary for patient empowerment (self-esteem, motivation, information, capacity, communication, patient-provider interaction, social support); threats and barriers to empowerment (human rights, DOTS typology, poverty, patient-centred care); and lessons to be learnt from empowerment and involvement (autonomy, acting for others, acting in collaboration with health care providers and TB programmes).

# Methods

The evidence and conclusions of this paper are derived from the published literature, reports, conference abstracts and information on the internet. The published literature in the MEDLINE and PSYCINFO databases was searched with the key words 'tuberculosis', 'patient' and '(participation or behaviour or incentive or empowerment or poverty or human right or patient right or community care)'. Each of the 314 articles initially retrieved was screened by reading the abstract. Only articles in which interventions or issues related to changing TB patients' behaviour or involving them in their own care or in TB control were mentioned were finally included in this review.

Abstracts were retrieved from abstract books distributed at conferences organized by the International Union against Tuberculosis and Lung Disease between 2003 and 2005, and the authors were contacted to obtain additional information when needed. Other conference abstracts and the 'grey literature' on TB patient empowerment or involvement were obtained through e-mail contacts and internet searches with the Google engine.

To make the review useful for operational decisions, practical experiences and interventions for empowering patients in TB care and control were sought. For each experience or intervention identified, the following information was systematically recorded: (1) description of the intervention (components, level of complexity) or experience and period of implementation; (2) the evaluation method (quantitative or qualitative, design); (3) implementation (challenges, useful ingredients, leaders or initiators); (4) the context (burden of TB, co-infection with HIV, other interventions, community role, first-line health services, nongovernmental organizations, TB control programmes); (5) measures or indicators of TB used and the results; and (6) the empowerment area explored, measurement indicators and results.



© IFRC/Chris Black

Operational definitions of empowerment and involvement of TB patients

Empowerment and involvement have been discussed in the context of other health problems, including HIV/AIDS (UNDP, 2004). Hibbard et al. (2004) defined the activation concept, which might be used as a general definition of empowerment and involvement. In this definition, the activated patient self-manages symptoms and problems, engages in activities that maintain functioning and reduce health decline, is involved in treatment and diagnostic choices, collaborates with providers, selects providers and provider organizations on the basis of performance or quality and navigates the health care system.

For the purposes of this review, the operational definition of the empowerment of TB patients is improving their capacity to better control their health and life, their ability to assist other TB patients in improving their lives (peer support) and their ability to assist TB control programmes and health care professionals.

---

#### **Better control by patients of their health and life**

The central component of the empowerment of TB patients is improving their capacity to take control of their own care and lives. This means that patients know and understand the diagnostic process and how to take their treatment. They are further capable of choosing a health facility and provider to assist them. Finally, they are able to cope with problems resulting from the disease. These aspects have been targeted by a number of educational interventions (Dick et al, 1996; Dick & Lombard, 1997b; Cabrera, Morisky & Chin, 2002; Alvarez Gordillo, Alvarez Gordillo & Dorantes Jimenez, 2003;). This component is a prerequisite for adherence as defined by WHO: "Adherence is different from compliance: The main difference is that adherence requires the patient's agreement to the recommendations... Patients should be active partners with health professionals in their own care." (WHO, 2003). Similarly, it is a condition for concordance, which "embraces the initial agreement between patient and healthcare provider, and also measures for ongoing support for patients to enable them to complete treatment. This is relevant to successful outcomes of treatment of communicable and non-communicable disease." (Maher et al, 2003). Both adherence and concordance imply a tacit contract between provider and empowered patient.

An evaluation of the Penduka project in Namibia expresses this first definition of empowerment very well: "By seeking to enable patients to complete their TB treatment, the Penduka TB project can be seen as an attempt to give patients agency in their own life. It's about gaining a possibility to be in control, to act and make changes in their life situation, regarding health, social and economic aspects. Agency can be defined as 'An actor engaged in a project...[with] a more active projection of the self toward some desired end' .... It refers to aspects of meaning and power. The patient participates in meaningful activities and through that gains power to act." (Augland, 2005).

---

#### **Peer support**

Health services alone cannot respond to all the needs of TB patients. Allies are needed. In this respect, patients and cured TB patients appear to be effective partners. One component of patients' empowerment and involvement is therefore reflected in their capacity to help other TB patients to overcome difficulties in their journey to care. This form of empowerment demands specific conditions (i.e. not all former TB patients can act as a peer carer) and is not adequate for all aspects of care (i.e. providing information about medical issues or handling complex medical problem) (Norwegian Association of Heart and Lung Patients, 2003).

Several examples of peer or TB patients' involvement in the care of other patients have been reported from the United States. Teenagers who completed their treatment acted as counsellors in the context of latent TB treatment for other teenagers (Morisky et al, 2001); in Harlem, New York City, cured patients monitored the treatment of other TB patients, using their personal experience to motivate them (Gie, 2001). In other settings, members of vulnerable groups acted as coaches for the adherence of Latino teenagers (Hovell et al, 2003) and injection drug users (Chaisson et al, 2001).

In community DOTS, the role of TB patients or cured TB patients is rarely mentioned, although they often support other TB patients, as in Orissa State (India) (Raye, Nayak & Nayak, 2005), the United Republic of Tanzania (Wandwalo et al, 2006; Wandwalo et al, 2004), Zambia (Bond et al, 2005) and Ethiopia (Getahun & Maher, 2000). In Katutura, Namibia, patients are part of a 'buddy system', in which the buddy is a person, fellow patient, family member, neighbour or friend designated by the patient to collect his or her medicine and perform DOTS at home when the patient cannot attend the Penduka project (Augland, 2005). In Zambia, persons living with HIV/AIDS and former TB patients help other patients to adhere; they organize group activities to give information, teach pill-taking techniques, conduct regular home visits to provide psychosocial support, assess adherence to drugs and relay data to the TB centre health team. This activity is made possible by creating good relationships with other patients (Mwape & Hirota, 2005).

---

### **Assisting TB control services**

Another component of the empowerment of TB patients is to enable them to assist TB programmes through advocacy, social mobilization and other activities. In concrete terms, TB patients (mainly cured) provide a positive image of persons affected by TB and of the way TB care is organized. In South Africa, for example, collaborative activities have been structured between programmes for HIV and TB care. Much of the experience of community involvement in South Africa has been in empowering for advocacy and better care. The Treatment Action Campaign was instrumental in mobilizing persons living with HIV/AIDS and affected communities and has recently added TB to its agenda (WHO, 2005c). In Cambodia, Mith Chouy Mith assists persons living with HIV/AIDS to share their experiences in the context of TB care and become advocates (Natpratan, 2005). In Bangladesh, cured TB patients are invited to help in case finding and also in social mobilization (Salim et al, 2003; Akramul, 2005). In Malawi in the 1990s, hospitalized TB patients elected a chairperson to check that all patients had correctly taken their treatment (Banerjee, Salaniponi & Harries, 1997). In Mongolia, cured TB patients share their experience with TB patients under treatment; they refer suspected cases to the TB centre and assist TB patients in following their treatment (He et al, 2005). In Viet Nam, cured TB patients are sometimes considered by the community as advisers or 'brokers' on TB issues (Johansson & Winkvist, 2002). In Mexico, peers conduct educational activities with persons living with HIV/AIDS to advocate better lung health (Rosas, 2005). In Canada, following a study on socio-cultural factors that influence the prevention and treatment of TB in immigrant and aboriginal communities, the authors discussed the role that lay people could play, particularly those who have recovered from active TB, their family members and health workers in the community, in adequately transmitting information to the population at risk (Gibson et al, 2005).

---

The Lusog Baga (healthy lungs) group is an organization for TB patients and cured patients in Manila, Philippines. The group provides peer support for treatment and has a seat on the Country Coordination Committee of the Global Fund to Fight AIDS, Tuberculosis and Malaria. The group was initiated by Dr Vivian Lofranco, who recognized that cured patients were an important resource in the fight against TB.

The group was established in 2001, with 15 members, was officially registered in 2005, and now has about 100 members. The president is Mr Fernando L. Collera (far left in the photograph). Most of the group's activities are conducted in the local community, but it also represents TB patients in national fora, such as the Country Coordinating Mechanism and the Philippine Coalition against TB.





© IFRC/Chris Black

## Barriers to empowering TB patients

Various barriers can impede the real empowerment of TB patients. Issues such as human rights for TB patients, patient-centred care and equity in relation to poverty and gender have been thoroughly discussed. The human rights approach stresses TB patients' right to non-discrimination and information as an integral part of achieving the right to health (WHO, 2001). Addressing poverty in TB control includes not only the needs of those facing economic impoverishment but also all relatively vulnerable, disadvantaged, marginalized, stigmatized and otherwise excluded sections of the population (WHO, 2005a). Looking at the patient at the centre of TB care implies looking at how T

Various barriers can impede the real empowerment of TB patients. Issues such as human rights for TB patients, patient-centred care and equity in relation to poverty and gender have been thoroughly discussed. The human rights approach stresses TB patients' right to non-discrimination and information as an integral part of achieving the right to health (WHO, 2001). Addressing poverty in TB control includes not only the needs of those facing economic impoverishment but also all relatively vulnerable, disadvantaged, marginalized, stigmatized and otherwise excluded sections of the population (WHO, 2005a). Looking at the patient at the centre of TB care implies looking at how TB patients' values, preferences, needs and expertise are considered (WHO, 2005b)

A number of intertwined threats and barriers that can hamper patients' empowerment were identified in this review: general barriers to accessing health services, particularly for the poor, women and other vulnerable groups; stigmatization and isolation of and discrimination against TB patients; 'patient control' in TB programmes; and belonging to vulnerable groups.

---

### **Barriers to accessing health services**

Obviously, suffering and illness as a consequence of TB are a barrier for empowering TB patients. Therefore, the first barrier is impeding their access to good TB services. The barrier can be geographical, economic, cultural or even intra-institutional (because of lack of care integration, for example).

The population as a whole and specific groups can be affected by these barriers. For instance, in some contexts, women appear to meet more barriers to care than men. Men and women differ with regard to care seeking and treatment behaviour, including differences in self-image, status in both the family and society, access to resources, the manifestation and expression of symptoms and the stigma associated with TB. With respect to treatment in the health system, gender differences are notable in the choice of provider, provider bias, acceptance of sputum examinations and non-acceptance of a diagnosis of TB. While women might have to negotiate more barriers in finding TB treatment, they tend to be more compliant than men (Uplekar, Rangan & Ogden, 1999). Other examples of selective barriers for specific vulnerable groups

have been reported ( Dutton, 1986; Needham, Godfrey-Faussett & Poster, 1998; Karim et al, 2003; Dandona et al, 2004; Eastwood & Hill, 2004; Sanou et al, 2004; van der Oest et al, 2005).

---

### **Stigmatization and isolation of and discrimination against TB patients**

The stigmatization of patients with TB alone or in association with HIV is today recognized as an important issue in TB control, affecting underprivileged groups, such as women, in particular (Atre et al, 2004). It can be a determinant in access to care and treatment regularity (Liefoghe et al, 1997; Alvarez-Gordillo et al, 2000; Lawn, 2000; Needham et al, 2004). The prejudices of health personnel or the community can also result in self-isolation and decreased self-esteem of the patient (Macq et al, 2005), which hamper patients' potential for empowerment and involvement.

---

### **'Patient control' in TB programmes**

Strict, universal application of DOTS can decrease the effectiveness of TB control (Lienhardt & Ogden, 2004). In its initial stages and even today in some contexts, DOTS is wrongly perceived as an intervention to 'control' the swallowing of TB drugs by nurses and other health care providers, often obliging patients to stay away from their families. Implementing DOTS in this way diminishes patients' empowerment. Enlarging the scope of the TB care helps in identifying patients' needs and transfers the responsibility for programme failures to managers rather than to patients (Hurtig, Porter & Ogden, 1999). Current trends favour flexible forms of DOTS, with the aim of supporting TB patients, giving more emphasis to patient-centred factors and the local context (Macq et al, 2003; Stop TB Partnership & WHO, 2006).

---

### **Belonging to vulnerable groups**

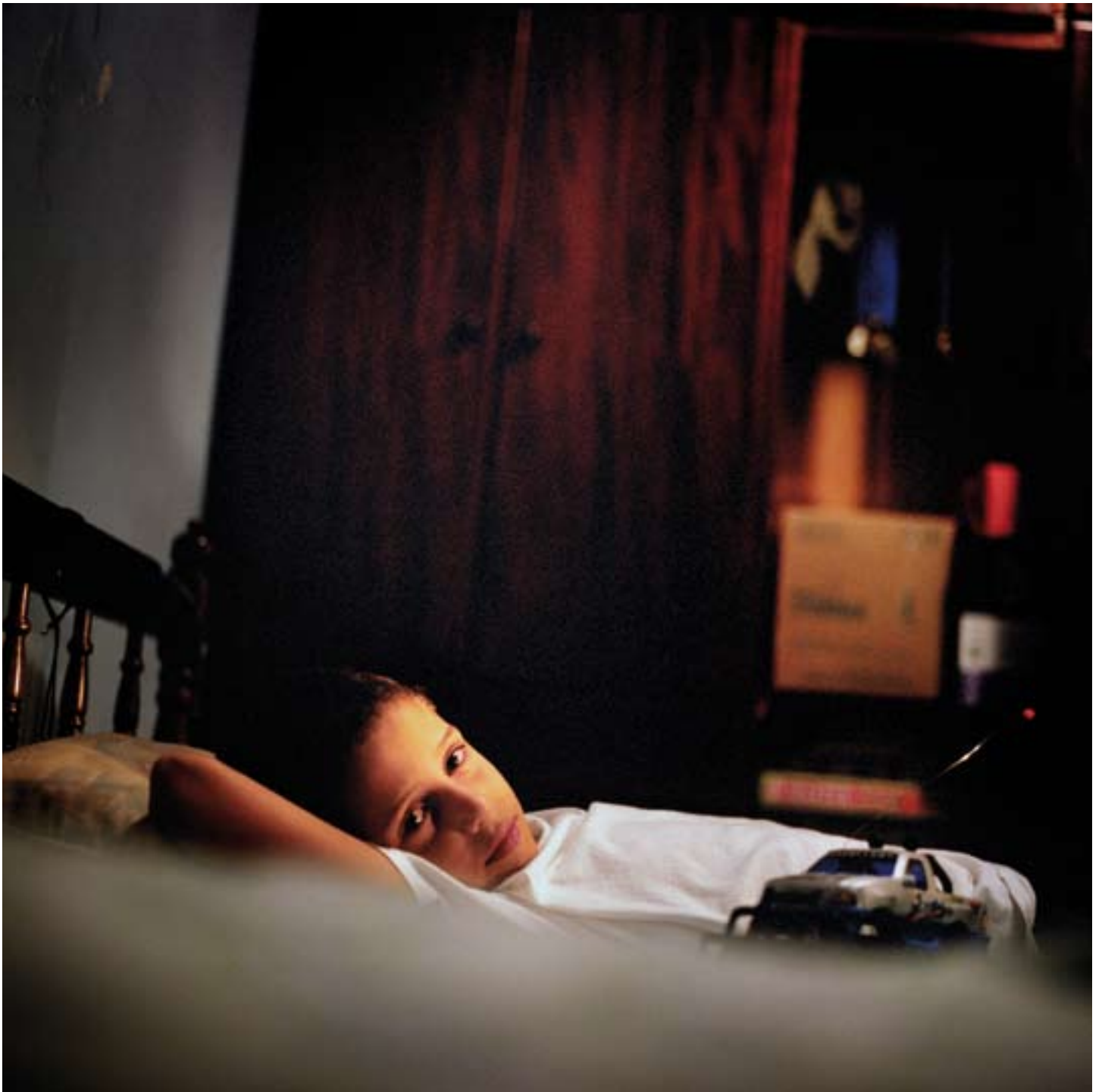
The characteristics of TB patients, and especially their affiliation to vulnerable groups such as prisoners, women, the poor and cultural minorities, can raise more barriers to their empowerment. One of the reasons is the classical approach of linking infectious disease and vulnerable groups, which places the responsibility for change on individuals. This approach has been criticized because it ignores social and economic factors that constrain the ability of an individual to change. More recently, attention has shifted towards improved understanding of the many complex processes that interact in making different individuals and communities vulnerable to infection, as discussed in the context of TB, HIV infection and malaria (Bates et al, 2004).

The importance of giving priority to activities to support vulnerable groups of TB patients has been recognized in various contexts. In the United States for example, cultural minorities have been targeted for specific interventions aiming at strengthening TB control (Cabrera et al., 2002; Hovell et al., 2003).

---

A group of people living with HIV/AIDS in Kabwe, Zambia, comprises TB patients who are HIV-positive. The group, recently established by Winston Zulu, does peer work and TB advocacy.





Experience with empowerment  
of TB patients

Various experiences with the empowerment of TB patients have been reported. These fall into four categories: enabling patients to take more responsibility for their health, and particularly treatment adherence; organizing TB patients into groups and clubs; instituting more patient-centred TB and general health care; and improving the advocacy skills of TB patients.

---

#### **Enabling TB patients to take more responsibility for their health**

Strengthening the ability of TB patients to better control and be involved in their treatment has been attempted by motivating adherence to treatment, providing information about the disease and its care, enhancing economic development and strengthening patients' capacity.

*Motivating* patients through specific interventions has been reported in South Africa and the United States. In South Africa, motivational interview techniques have been used to increase patients' motivation and centredness during consultations (Allen & Dick, 2003). In the United States, interventions to motivate patients to adhere and take an active part in their treatment have been tested (Cass et al, 2005).

Tools for *informing* patients have been tested in various contexts. Experiences have been reported from Ghana (Martin et al, 2005), India (Datta & Nichter, 2006), Mexico (Alvarez Gordillo et al., 2003), South Africa (Dick et al., 1996; Dick & Lombard, 1997a) and the United States (Cabrera et al., 2002; Houston, Harada & Makinodan, 2002). Additionally, the Centers for Disease Control and Prevention in the United States have made available a library of educational material for this purpose (Centers for Disease Control, 2006). Efforts have been made to design culturally sensitive tools and to use them in the context of patient-centred care (Dick & Lombard, 1997a; Datta & Nichter, 2006).

As most TB patients live in poverty, enhancing their economic *capacity* to pay for care could contribute towards empowerment. The provision of small loans to the families of TB patients to assist them in generating more income and therefore increasing their financial autonomy was reported from Cambodia (Sok, Shapiro & Goldfeld, 2004). Temporary food assistance can also be an important condition for empowerment and is now often provided as part of TB care (Bond et al, 2005). Such adjuncts to TB therapy could confer socioeconomic and survival benefits (Paton et al, 2004).

In some settings, combined interventions for motivation and information have been used to strengthen patients' capacity. In Harlem, New York City, United States, in an attempt to strengthen patient adherence to latent TB treatment, the informational–motivational–behaviour model was proposed for educating patients and changing their behaviour. The first prerequisite of this model is information, which includes basic knowledge and patients' beliefs about the targeted behaviour, which might differ from the information that health care providers convey. Motivation to practise the behaviour depends on perceptions of individual vulnerability, the costs and benefits of the targeted behaviour and social support or social norms when engaging in the behaviour. Specific behavioural skills, including appropriate strategies and tools, are necessary to execute the targeted behaviour. In the informational–motivational–behaviour model, providing information and strengthening motivation precede teaching the behavioural skills that are ultimately needed to initiate and maintain the desired behaviour (Franks, Colson & Hirsch-Moverman, 2005). Other multifaceted approaches have been reported from Namibia and Thailand.

In the Penduka project in Namibia, DOTS points have been organized, which are located close to the places where TB patients come to take their treatment. The innovative component is the organization of various supportive activities throughout the week. Each DOTS point has a weekly schedule of two days for handicraft training and another two for health education. No activity is assigned to the fifth day, although the patients come to eat and take medicine. Every day, between 08:30 and 11:30, patients in the project have to be at the DOTS point nearest to their home. Throughout treatment, patients meet other people who are also poor and sick with TB (Augland, 2005).

In Thailand, a comprehensive package of intervention has been used to strengthen capacity and enhance behaviour skills among prisoners with TB (Ngamtrairai & Jittimanee, 2004)

---

### **Organization of TB patient groups and clubs**

The second type of experience is empowering TB patients by making them part of a group that shares their problems, in associations, clubs and self-help groups. In Ethiopia, TB clubs and associations act as self-help groups for social mobilization (Getahun, 1998; Getahun & Maher, 2000; Demissie, Getahun & Lindtjorn, 2003). In Nicaragua, clubs for persons affected with TB are also structured mainly as self-help groups (Macq et al, 2004). In Ecuador, similar groups create interactions between cured and new patients to motivate the latter to adhere to treatment (Soares & Cesar Cavalcante, 2004). In Bangladesh, TB groups are organized as part of an overall programme run by a nongovernmental organization (Akramul, 2005). In Mumbai (India), the TB programme holds meetings with patients to enable them to share their experiences (Rangan et al, 2003b). In Mongolia, in a context of TB stigma and low case detection, TB clubs have been organized with cured patients, patients under treatment and community leaders (He et al., 2005). In Chiapas, Mexico, TB clubs were organized during a short period as part of a study (Alvarez Gordillo et al., 2003). In Oruro (Bolivia) and in Toribio (Colombia), TB clubs were reported as part of a community care programme. In Oruro, the programme has existed for over 10 years (Jaramillo, 2002). In Ndola (Zambia), former TB patients have created health education committees, which give talks about TB, thereby reducing the stigma linked to the disease (Harries et al, 2001). In Peru, group therapy sessions have been established for patients with multidrug-resistant TB. Former patients continue to participate by providing testimony to others who are still under treatment (Shin et al, 2004) and providing psychological and financial support for TB patients and suspected patients (Getahun & Maher, 2000). Also in Peru, TB patients in two hospitals and 24 health centres of Coma constitute the base of a nongovernmental organization (Asociación de Enfermos de Tuberculosis, 2006).

---

### **Instituting more patient-centred TB and general health care**

Although TB control programmes have aimed at achieving the highest possible coverage of diagnosis and treatment, it has become clear that coverage, particularly of underprivileged persons affected by TB, can be extended only by going beyond diagnostic techniques and treatment schemes. Various authors have shown that customized strategies are needed to help persons affected by TB overcome the social and economic barriers to cure (Farmer, 1997; Ogden et al., 1999; Macq et al., 2003, 2004b; Needham et al., 2004; Sanou et al., 2004). Such strategies have often been called 'patient-centred'.

The two definitions of the patient-centred approach given by Michie et al. (2003) are useful in changing from standard biomedical care to customized, more comprehensive care of TB patients. In the 'patient activation' approach, patients actively take some control, ask questions or speak spontaneously about their concerns. Empowerment need not involve decision-making but must involve an active role in consultation. In the 'patient perspective' approach, patients' beliefs are elicited and responses made to them. The beliefs might be matched within the consultation or emphasis might be laid on patient-centred behaviour by the health professional, for example, by asking patients open questions about personal or social issues.

Health care providers and managers are not only adapting realities to the care of TB patients, thus helping them to overcome barriers, but are also recognizing the positive role that mainly cured TB patients can play in strengthening TB programmes. This has been illustrated in some community care experiences (Stop TB department, 2003).

A number of interventions have been made to improve the focus of health care and TB programmes on TB patients' needs and capacities. A central element in this respect is the patient-provider interaction. The results of a randomized clinical trial in South Africa to test interventions for improving communication and the patient-provider interaction were, however, not conclusive (Dick et al, 2004; Lewin et al, 2005). One of the reasons may be that the success of such interventions depends on contextual factors, including cultural factors. This is a complex issue that requires carers to have a number of skills. For example, Crafton and Galanowsky (2004) proposed six steps for developing care with a cultural input, each requiring specific skills: (1) Involve patients in their own health care. (2) Learn more about culture, starting with your own. (3) Speak the language, or use a trained interpreter. (4) Ask the right questions and look for answers. (5) Pay attention to financial issues. (6) Find resources and build partnerships.

Other experiences and interventions have gone beyond the patient–provider interaction. In Orissa, India, the ‘trialogue’ approach has been identified as of particular importance in interpersonal communication among providers, patients and the community. Triologue aims to change community attitudes and behaviour through active participation in caring for persons affected by the disease and through open, honest discussions about fears, prejudices and problems associated with TB. It has an impact on the patient–provider interaction and allows action against stigmatization (Raye, Nayak & De Munynck, 2005). In Nicaragua, a package of interventions was tested in five municipalities, with the aim of improving the interaction between health care providers and TB patients and eliciting a more positive image of TB patients from the care providers’ point of view. It included discussions of patient problems, revision of patient flow and home visits by two providers to observe the patients’ social context (Macq et al., 2004). In the United States, the Harlem surrogate family model DOTS clinic is an on-site programme in which patients are attracted to the clinic by the provision of consistent personal support, food, tokens and other forms of tangible assistance in a warm, supportive atmosphere, with possible referral to substance abuse counsellors, social workers and health educators (El Saadr, 2006).

---

### **Improving the advocacy skills of TB patients**

Advocacy and activism movements have evolved mainly at a ‘macro’ level, nationally and internationally, but also at a local level, to claim greater participation in decisions and a ‘voice’ for TB patients and affected communities. The report of a workshop held in New Delhi, India, in 2004 stated that the TB community is not a professional community and decried the idea that TB is ‘owned’ by well-meaning public health officials. The TB community should therefore be opened to create greater dynamism, and access to information on TB–HIV should be facilitated. ‘Ownership’ of response should be transferred from Stop TB and WHO, for example by encouraging the formation of more TB patient groups and training them in advocacy skills, such as use of the media to highlight particular issues (Stop TB Partnership, 2004).

Local initiatives have aimed at giving a voice to TB patients in decision-making, in organizing TB programmes and in gaining control over their care. In Nepal, TB patients are invited to take part in local DOTS committees (Bam et al, 2004b), and, in Burkina Faso, TB patients participate in local meetings with other stakeholders (Dembele et al, 2003).

At the national level, advocacy has been used to promote a better place in society for TB patients. In Brazil, mobilization campaigns have been organized on the human rights of TB patients (Tavora et al, 2004). In Mexico, the ‘white flag’ strategy promotes TB patients within communities (Macedo, Ferreira & Castellanos, 2003).

Worldwide, TBTU, a nongovernmental organization, has promoted a charter for the TB community conjointly with international standards for TB care (Case, 2005). The charter outlines the rights and responsibilities of persons affected by TB, thus empowering patients and their communities. Initiated and developed by patients around the world, the charter makes the relationship with health care providers a mutually beneficial one (Case, 2006). Along the same lines, a manifesto was circulated during the 2005 conference of the International Union Against Tuberculosis and Lung Diseases, calling for stronger political commitment to make TB care more accessible to affected persons (Treatment Action Group, 2006). Some individual TB patients are also promoting the rights of people affected by TB, for instance Winston Zulu (Hampton, 2006) and Lucy Chesire (Chesire, 2006).



Operationalizing  
TB patient empowerment: lessons learnt

Experiences and interventions to empower and involve TB patients are usually complex and thus comprise a number of elements. The ‘active ingredient’ of an effective intervention is often difficult to specify (Campbell et al, 2000). For such interventions, the experiences that have been reviewed show that evaluation and planning for scale-up should take into consideration potential barriers and contextual issues specific to the local situation.

---

### **Stakeholders**

Various types of stakeholders played active roles in the experiences and interventions for empowering and involving TB patients. We identified nongovernmental organizations, community-based organizations, TB programmes, front-line and first-line health services, academic institutions, persons living with HIV/AIDS and, of course, TB patients.

The first group of stakeholders involved in patient empowerment should be TB patients themselves. It is striking, however, that patients with TB have usually had a relatively marginal role in initiating empowerment. The Asociación de Enfermos de Tuberculosis, a nongovernmental organization in Peru run by TB patients and the Norwegian Association of Heart and Lung Patients, is exceptional in this respect, partly because they have existed for some time (since 1943, in the case of the Norwegian Association) (Asociación de Enfermos de Tuberculosis, 2005; Myrseth, 2006).

The community of persons living with HIV/AIDS and activists have begun to pay attention to TB epidemics and the access to care of affected persons. This has been helpful in bringing some form of activism to the TB patients’ community, as the concept of patient empowerment is much more developed in the organization of care of persons living with HIV/AIDS. We identified two experiences in which TB and lung health were addressed by organizations for persons living with HIV/AIDS ( Natpratan, 2005; Siddhi & Kafle, 2005).

The second important group of stakeholders in empowering and involving TB patients is nongovernmental organizations. Care for TB patients is the main mission of some, such as the Damian Foundation (Salim et al., 2003). Many, however, do not limit their mission to the care and empowerment of TB patients, as is the case of the Bangladesh Rural Advancement Committee and some organizations in India (Rangan et, 2003a,b), which have a much broader agenda (Akramul, 2005). Their activities are sometimes coordinated with national TB control programmes (Rangan et al., 2003a) and sometimes less obviously so (Natpratan, 2005).

Surprisingly, the role of front-line health care workers and first-line health services in the empowerment and involvement of TB patients has been addressed to only a limited extent. The variety of roles they can play in TB empowerment and involvement (as peer workers, developing a patient-centred approach) has been highlighted by Torfoss (2006) and taken up by authors in South Africa (Dick et al., 2004), West Africa and Nicaragua (Macq et al, 2005).

Many experiences or interventions to empower TB patients are actually research projects initiated by academic institutions, for example in Mexico (Alvarez Gordillo et al, 2003), Nicaragua (Macq et al, 2005) and the United States (Morisky et al, 2001; Cass et al, 2005). Researchers and academic institutions have the possibility of trying new strategies and evaluating them.

TB programmes have always had a role to play in empowering TB patients, at least in ensuring the availability of diagnostic materials and drugs. Some programmes, however, initiate new experiences or interventions, as for example in Burkina Faso (Dembele et al., 2003) and Malawi (Manders et al, 2001).

Activities and experiences to empower TB patients often require concerted decisions and actions. It is therefore important to develop coordination among stakeholders who might not be used to working together. In West Africa (Benin, Burkina Faso, Mali and Senegal), a project is under way to help TB control managers, front-line health care workers, academics and health system managers to institute more TB patient-centred care and enhance coordination (Drabo et al, 2006)

---

### **Incentives and enablers**

Incentives and enablers underlie many interventions to empower and involve TB patients. Enablers help patients to change their behaviour, while incentives can be used to motivate patients. Even if patients have intrinsic motivations (altruism, filling their spare time, the novelty factor), the attrition rate in participation in TB control or the care of other TB patients can be high (Kironde & Klaasen, 2002).

Enablers have been discussed in previous sections. For example, training has been organized for former TB patients to help new TB patients in taking their treatment (Chaisson et al, 2001; Hovell et al, 2003; Wandwalo et al, 2006), and handicraft activities have been organized to enable TB patients to better cope with their economic problems (Augland, 2005).

Incentives are usually provided to TB patients in the context of other interventions and can take the form of food supplements (Augland, 2005), calendars with stickers and toys (Cass et al., 2005) or symbolic honouring of patients (for example during meetings) (Rangan et al., 2003b). A central element of an incentive is its cost and its sustainability, as starting an incentive mechanism and having to stop it because of lack of resources can be worse than doing nothing.

---

### **Performance of TB control programmes**

The performance of a TB programme can influence strategies to empower and involve TB patients and will, of course, also influence the results of such interventions. The results will usually be more impressive in an initially poorly performing TB control programme. Some of the reported experiences and interventions were part of an overall strategy to strengthen a programme with initial poor performance. In Ethiopia, TB clubs were started while the TB programme was being rehabilitated (Getahun & Maher, 2000). In Orissa, India (Raye et al., 2005) and in Nepal (Bam et al, 2004a), activities to empower TB patients were part of an overall package to strengthen the TB control programme.

Other TB control programmes, such as in India, Malawi, Nicaragua and Peru, have matured over the years and have thus been able to organize adequate diagnosis and treatment facilities in public health services. This experience might be an argument for enlarging the scope of activities within a programme. When a programme reaches a high level of performance, it should progressively start tackling issues such as the fears, anxieties and perceptions of patients about their illness, cure and empowerment (Rajeswari et al, 2005). This logic has been followed, for example, in Nicaragua (Macq et al, 2004).

---

### **Burden of TB**

The burden of TB can influence the kind of empowerment and involvement intervention that is used. Institution of TB community care and the involvement of lay people and the community in TB care have been much more frequent in areas where the burden of TB is high and the pressure on health services therefore great. Similarly, involving TB patients as DOTS supporters has been mainly reported in such contexts, for example in the United Republic of Tanzania and Zambia (Bond et al., 2005).

Strategies for peer support and for acquisition of behavioural skills are usually reported in well-defined and vulnerable groups (adolescents, intravenous drug injectors, persons living with HIV/AIDS, prisoners) and not in contexts with a high TB burden (Gie, 2001; Ngamtrairai & Jittimane, 2004; Natpratan, 2005).

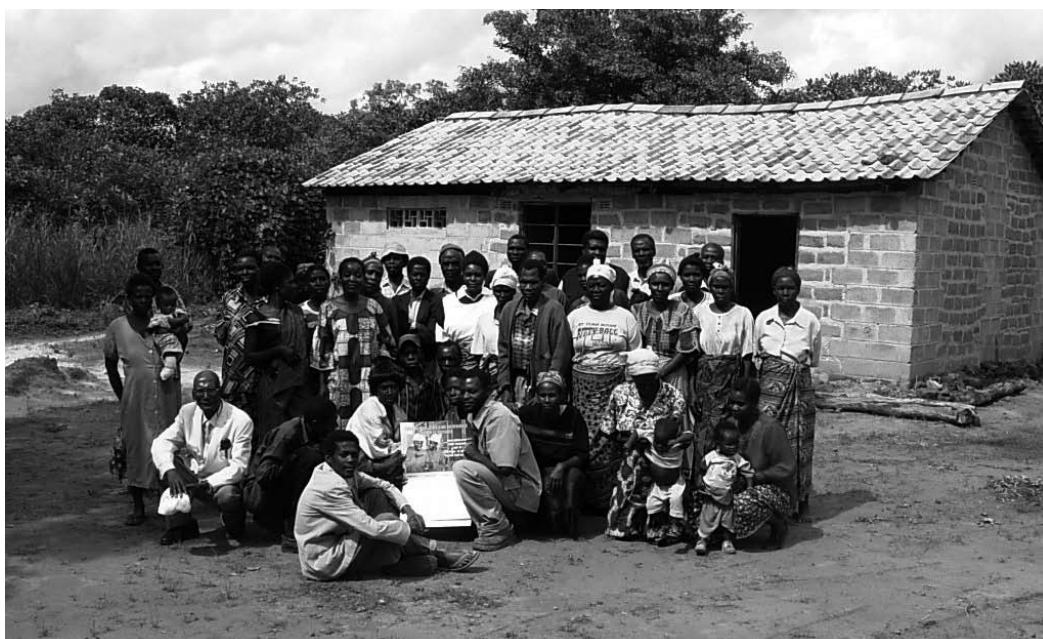
---

### **Resource availability and sustainability**

Empowering and involving TB patients can reduce the cost of TB programmes, when for example cured patients are DOTS supporters. It can, however, increase costs when, for example, it involves motivating or training interventions or the organization of TB clubs. Some of the costs of such interventions have been reported in the literature. For example, the cost of a structured behavioural intervention to enhance adherence to latent TB treatment in a TB clinic in San Diego, United States, was evaluated at US\$ 3 per child (Cass et al., 2005).

---

The Masaiti group of cured TB patients was started recently in Copperbelt Province, Zambia, with help from health workers and a local nongovernmental organization, the Copperbelt Health Education Project. The group does peer work, supports patients in adhering to treatment, and carries out TB information activities. It generates income by growing vegetables, which are also given to needy patients.





Scaling-up an experience or intervention

An evaluation for scaling-up must address all the issues mentioned above, as most of the experiences are small-scale trials or pilot projects. Only a few larger initiatives have been reported, mainly in Asia [Bangladesh (Akramul, 2005; Salim et al., 2003), India (Rangan et al., 2003a,b) and Nepal (Bam et al., 2004a) and in Mexico (Macedo et al., 2003). The success of a project to empower TB patients depends on context-specific elements, which vary from one country to another. Therefore, a 'one size fits all' approach will not work. Particular attention should therefore be given to the evaluation of small-scale interventions.

Unfortunately, many innovative experiences have been reported with no clear mention of evaluation (Table 1). Empowerment strategies are not easy to evaluate, and experimental methods alone cannot be used (Wallerstein, 2006). Several aspects must be considered: evaluation of the process, evaluation of the outcome for TB control, evaluation of the outcome for the patient's well-being and evaluation of the outcome for equity. Methods for reporting and measuring these aspects have been insufficiently addressed, and most evaluations focus on the effects of an intervention on the process of TB diagnosis or treatment

TABLE 1. EXPERIENCE OR INTERVENTION WITHOUT FORMAL EVALUATION REPORTED

Reference	Intervention or experience
Bam et al. (2004a,b)	Countrywide implementation of DOTS committees involving various local actors, including TB patients and their families, from 1994 to 2000. The treatment center was established only after the local DOTS committee was functional.
Dembele, Poda & Dauby (2003)	Promotion of shared decision-making in the organization of local participatory meetings involving patients, providers, programme manager and community representatives in three districts of Burkina Faso. Initially, active patient participation in such meeting was difficult, as some are afraid to express their problems because of the presence of health care providers or programme managers that might represent authority for them.
Tavora et al. (2004) Basic information on social mobilization against TB in Brazil in <a href="http://www.cve.saude.sp.gov.br/htm/tb/evento_mov.htm#">http://www.cve.saude.sp.gov.br/htm/tb/evento_mov.htm#</a> accessed in December 2005	Successful approach for social mobilization for AIDS control translated for TB in collaboration with 35 civil society organizations in Rio de Janeiro, Brazil. The purpose of the intervention was to influence public health policies and denounce all kinds of human rights omissions, transgressions and violations suffered by people living with TB.
Gie (2001) See also information on <a href="http://www.harlemtbcenter.org/abstracts/abs_2001_effect_peer_worker_in_treatprog.htm">http://www.harlemtbcenter.org/abstracts/abs_2001_effect_peer_worker_in_treatprog.htm</a>	Peer workers enhance adherence to treatment for latent TB infection in Harlem, New York City, United States. Peer workers are members of the same community, who have successfully completed TB treatment. They often use personal experience to convince patients to initiate treatment or to remain adherent. The challenge for peer workers is to present treatment completion positively, emphasizing the skills the patient has acquired while adhering and meeting daily needs.
Allen & Dick (2003)	Since 1992, a social activation strategy called 'white flag' has been used to enhance health promotion around TB and TB patients. It consists of certification of a community that has been evaluated by a State committee. After 7 months, there were 705 white flag communities.
Macedo et al. (2003)	Qualitative evaluation showed that most patients treated in the community (83%) and in a health facility (79%) were willing to supervise treatment. Most were willing to supervise another TB patient because they had personal experience of the disease (80%) and would like to help another patient. Others (13%) were willing to supervise another patient in order to reduce the burden of TB in the community. A few (7%) were willing to supervise only a family member.
<a href="http://www.msh.org/projects/rpmpplus/3.5.5h.htm#latinamerica">http://www.msh.org/projects/rpmpplus/3.5.5h.htm#latinamerica</a> (accessed December 2005)	Implementation of TB clubs in Ecuador as a means for former TB patients to motivate new ones

TABLE 1. EXPERIENCE OR INTERVENTION WITHOUT FORMAL EVALUATION REPORTED

Reference	Intervention or experience
Rosas (2005)	In Mexico, in the context of a project to raise awareness of the need to integrate TB-HIV, peer education of persons living with HIV/AIDS, empowering them to advocate better lung health services within a human rights framework
Akramul (2005)	In Bangladesh, intervention in 283 sub-districts covering 82 x 10 <sup>6</sup> inhabitants. Female community health volunteers play a pivotal role in educating the community and ensuring DOTS. DOTS committees function at various levels with TB patients participation. TB clubs are organized to increase involvement of TB patients in identifying and referring cases.
Case (2005)	Worldwide, through a nongovernmental organization (TBTv): promotion of the concept of positively empowered patients and design of a patient charter for the TB community
Natpratan (2005)	In Cambodia, the main activity of Mith Chouy Mith or 'friends helping friends' is a monthly meeting to coordinate comprehensive care for persons living with HIV/AIDS and TB. These persons are given the opportunity to share their experiences and capacity building for advocacy. The result (no data presented) has been less discrimination by hospital staff and better attendance of persons living with HIV/AIDS. A network has been established.
Raye, Nayak & Nayak (2005)	A positive role played in Orissa State, India, by cured TB patients as DOTS providers.
Rangan et al. (2003a,b) See also p. 42 in WHO (2005b)	In Mumbai, India, a wide variety of nongovernmental organizations support patients and training. Patients' meetings are run regularly in clinics to enable them to share their experiences and ask questions about their diagnosis and treatment. A meeting was held during World TB Day to congratulate patients who completed their treatment.
Johansson & Winkvist (2002)	Former patients act as 'brokers' in Quang Ninh Province in Viet Nam where there is a relatively high rate of HIV infection. They play an advisory role in the community on the basis of their experience. No structured network, but people in the community know where they are.
Asociacion de Enfermos de Tuberculosis (2005)	A TB patients' nongovernmental organization in Peru, which has been defending TB patients since 1976
He et al. (2005)	In Chifeng, Mongolia, in a context of TB stigmatization and low case detection, clubs organized for TB patients under treatment or cured, local officers, celebrities and leaders of health organizations. TB patients share their experience with other patients, and community leaders give speeches; cured TB patients identify suspected cases and observe treatment adherence. TB stigmatization said to be greatly reduced, but no data available.

### Evaluation of the process

In evaluating experiences or interventions to involve or empower TB patients in TB control, it is essential to understand the process. The literature that was reviewed highlighted the following elements:

- the rationale for starting the intervention, as in the experience with TB clubs in Ethiopia (Demissie et al., 2003) and in interventions for reducing stigmatization in Nicaragua (Macq, Solis & Martinez, 2004a);
- the interactions among stakeholders in implementation of the intervention, as partly presented for the United Republic of Tanzania (Wandwalo et al., 2006); and
- the essential ingredient of the intervention as implemented (Hovell et al., 2003; Salim et al., 2003).

### Outcome evaluation: TB control

Most of the evaluations of interventions and experience have focused on TB control, i.e. TB case detection, adherence to treatment (including for latent TB) and outcome of treatment. No evaluations of experiences with 'TB communities' led by TB patients have been reported, perhaps because such empowering experiences are new or are difficult to conduct.

Six randomized controlled trials and six studies with quasi-experimental or observational designs were identified for evaluating other type of experience. The results generally showed a positive or neutral impact on TB control. We do not, however, wish to draw conclusions about the effectiveness of any type of intervention, mainly because their effects appear to be strongly related to the process and the context. Tables 2, 3 and 4 show the main features of the evaluations for TB control of experiences and interventions aimed at strengthening patients' capacity to adhere or to help others to adhere, organizing TB patients groups and clubs and instituting more patient-centred TB and general health care.

TABLE 2. STRENGTHENING PATIENTS' CAPACITY TO ADHERE OR TO HELP OTHERS TO ADHERE

Intervention	Type of study	Results
<b>Cass et al. (2005)</b>		
Structured behavioural intervention to enhance adherence to latent TB treatment (calendar with sticker and toy as an incentive), July 1995–December 1997 in TB clinic in San Diego, California, United States	Before–after retrospective study (741 interventions and 841 controls)	Logistic regression analysis demonstrated that children who participated in the intervention were 2.4 times more likely to complete therapy than those who did not
<b>Ngamtrairai &amp; Jittimane (2004)</b>		
Supportive–educative nursing intervention on self-care behaviour, March–April 2002 in correctional institution in Pathumthani and in Bangkok, Thailand	Quasi-experimental study (37 patients in intervention and 38 patients in control arm)	Not available
<b>Sok, Shapiro &amp; Goldfeld (2004)</b>		
Female-managed village bank microcredit schemes for families of TB patients, 1994–2001 in 96 villages in Cambodia	590 women in TB-affected families	Compliance and cure rate > 95%
<b>(Salim et al., 2003; MSH, 2001)</b>		
86 sessions to orient 2707 former TB patients organized by the Damian Foundation to stimulate TB patients. The Foundation organizes gatherings of cured cases within their own community. Cured patients are encouraged to act as advocates.	Observational descriptive study	Of 11 501 smear-positive cases, 28.5% were identified by former TB patients.
<b>Morisky et al. (2001)</b>		
Treatment for latent tuberculosis supervised by peer counsellors in two clinics in Los Angeles, California, United States, between 1995 and 1998. Peer counsellors are adolescents who completed treatment for latent infection. Counsellors were trained in their roles and responsibilities.	Randomized controlled trial comparing four groups of adolescents (11–19 years) treated for latent TB: peer counsellors; incentive contacts; combined peer counsellors and incentive contacts; usual care. 199 adolescents treated for latent TB with peer counsellor	Peer counselling had significant impact on medication-taking behaviour, which was strongly correlated with completion of care: 80.3% completed care in peer counselling group vs 77.3% in usual care group
<b>Hovell et al. (2003)</b>		
Comparison of coaching with self-esteem intervention for adolescents with latent TB in San Diego, California, United States.  Coaching intervention involved either initial training and monthly case review in which coaching procedures and advice on adherence were discussed, or initial interview, then subsequent interview (5.30' in-person sessions and 7.15' telephone sessions). Self-esteem counselling involved encouraging adolescents to discuss problems affecting their self-esteem	Randomized controlled trial comparing three groups of Latino adolescents treated for latent TB: adherence coaching done by Latino university student; self-esteem counselling done by Latino students; usual care. 286 Latino students randomly assigned to the three groups between October 1996 and January 2000	51.1% of coached adolescents, 41.8% of those in the self-esteem group and 37.5% in the usual care group completed treatment. No statistical significance

TABLE 2. STRENGTHENING PATIENTS' CAPACITY TO ADHERE OR TO HELP OTHERS TO ADHERE

Intervention	Type of study	Results
<b>Hovell et al. (2003)</b>		
<p>Comparison of coaching with self-esteem intervention for adolescents with latent TB in San Diego, California, United States.</p> <p>Coaching intervention involved either initial training and monthly case review in which coaching procedures and advice on adherence were discussed, or initial interview, then subsequent interview (5.30' in-person sessions and 7.15' telephone sessions). Self-esteem counselling involved encouraging adolescents to discuss problems affecting their self-esteem</p>	<p>Randomized controlled trial comparing three groups of Latino adolescents treated for latent TB: adherence coaching done by Latino university student; self-esteem counselling done by Latino students; usual care. 286 Latino students randomly assigned to the three groups between October 1996 and January 2000</p>	<p>51.1% of coached adolescents, 41.8% of those in the self-esteem group and 37.5% in the usual care group completed treatment. No statistical significance</p>
<b>Chaisson et al. (2001)</b>		
<p>Peer counselling, education and group support for injection drug users given preventive isoniazid therapy in Baltimore, Maryland, United States. Supply received once a month, meetings with peer counsellor twice during the first month of therapy and once the following month. Patients attended a monthly support group meeting, during which they received a lunch. Peer counsellors were former drug users who had completed isoniazid therapy and had received a training in counselling patients with TB and HIV infection.</p> <p>All patients received a US\$ 10 stipend for each month they adhered.</p>	<p>Randomized controlled trial with 300 persons assigned between June 1995 and September 1997 to: directly observed therapy; peer counselling and education; or routine care.</p>	<p>With direct observation, the median proportion of doses taken by the supervised group was 100%, while electronic monitoring in a subset of patients showed that the peer group (<math>n = 27</math>) took 57% of prescribed doses and the routine care group (<math>n = 32</math>) took 49% (<math>p &lt; 0.001</math>).</p>
<b>(Wandwalo et al., 2004, 2006)</b>		
<p>Community-based DOTS intervention in which the treatment supporter was either a guardian or a former TB patient. Former TB patients who had successfully completed treatment and lived close to the patient's home were selected by the district TB and leprosy coordinator.</p>	<p>Randomized controlled trial of 268 patients and 103 treatment supporters</p>	<p>Community-based DOTS was as effective as health facility-based DOTS, with treatment success rates of 85% and 83% (odds ratio, 1.17, 95% confidence interval, 0.75–1.83), respectively</p>
<b>(Banerjee, Salaniponi &amp; Harries, 1997)</b>		
<p>In the 1970s, a TB ward chairperson (a patient with TB) was elected by other TB patients to check that other TB patients correctly took their treatment. This was reintroduced in 1995 in Ntcheu District Hospital, Malawi.</p>	<p>Before–after comparison of 'patient-empowered' treatment (supervised by chairperson) (<math>n = 149</math>) and nurse-administered treatment (<math>n = 121</math>)</p>	<p>Outcome of TB treatment similar in the two groups</p>

TABLE 3. ORGANIZATION OF TB PATIENT GROUPS AND CLUBS TO STRENGTHEN THEIR INVOLVEMENT

Intervention	Type of study	Results
<b>Getahun (1998); Getahun &amp; Maher (2000); Demissie, Getahun &amp; Lindtjorn (2003)</b>		
<p>TB clubs initially organized by health personnel within framework of general strengthening of TB programme in two districts of Amhara State in northern Ethiopia</p>	<p>Quasi-experimental design with 128 patients enrolled (64 interventions and 64 controls), combined with qualitative study</p>	<p>Huge difference between intervention and control in default rates (12.5% vs 40.6%).TB clubs referred 181 suspected cases, 65% of which had a diagnosis of TB, and identified 69% of all patients and 76% of new sputum smear-positive pulmonary patients diagnosed in the district</p>
<b>Macq et al. (2004a); Macq, Solis &amp; Martinez (2006)</b>		
<p>In the context of a project to reduce TB stigmatization in five municipalities in Nicaragua, intervention to enable patient participation: TB clubs, home visits (sometimes by TB patients) and advocacy, between 2004 and 2006</p>	<p>Quasi-experimental design with 212 persons affected by TB. Comparisons of intervention and control groups for delay between symptoms and diagnosis, detection rate, success rate and proportion of patients who had completed treatment after 8 months.</p>	<p>Unpublished</p>
<b>Alvarez Gordillo, Alvarez Gordillo &amp; Dorantes Jimenez (2003)</b>		
<p>Launching of self-help groups during 2001 and training of providers (social and medical) to improve communication with TB patients in Chiapas, Mexico</p>	<p>Quasi-experimental design: 87 patients participated, 44 exposed to the intervention and 43 as the control group.</p>	<p>Compliance with treatment was considerably greater in the intervention group than in the control group (97.7% vs 81.4%, respectively; relative risk, 1.20; 95% confidence interval, 1.03 to 1.39; <math>p = 0.0015</math>)</p>

TABLE 4. INSTITUTE MORE PATIENT-CENTRED TB AND GENERAL HEALTH CARE

Intervention	Type of study	Results
<b>Lewin et al. (2005)</b>		
<p>Participatory in-service training for clinic staff from 1996 to 2000 in primary care clinics in Cape Town, South Africa, with less than 70% of cure rate</p>	<p>Cluster randomized controlled trial in which clinics were assigned to either the intervention (<math>n = 12</math>) or control (<math>n = 12</math>) groups. All clinics completed follow-up. Treatment outcomes measured in cohorts of adult pulmonary TB patients before the intervention (<math>n = 1200</math>) and 9 months after training (<math>n = 1177</math>).</p>	<p>Estimated effect of intervention was an increase in successful treatment rates of 4.8% (95% confidence interval, -5.5% to 15.2%) and in bacteriological cure rates of 10.4% (-1.2% to 22%). Training did not improve TB outcomes; however, the results were inconclusive.</p>
<b>El Saadr (2006)</b>		
<p>The Harlem surrogate family model DOTS clinic is an on-site programme attracting patients to the clinic by providing consistent personal support, food, tokens and other forms of tangible assistance in a warm, supportive atmosphere, with referrals to substance use counsellors, social workers and health educators.</p>	<p>Randomized controlled trial with 207 patients undergoing treatment for TB assigned to clinic-based 'surrogate family' model DOTS or community-based off-site DOTS</p>	<p>Completion rates were available for 177 patients. 73% of on-site patients and 77% of off-site patients completed TB treatment (<math>p = 0.697</math>). Of patients with confirmed TB, 95% of on-site patients and 99% of off-site completed treatment (<math>p = 0.334</math>). Preliminary analysis suggests that the clinic-based surrogate family model DOTS is as effective as community-based DOTS in achieving completion of TB treatment.</p>

### Outcome evaluation: patient well-being

As mentioned above, indicators of improved well-being are seldom used, perhaps reflecting the utilitarian approach to empowerment, involving TB patients for the benefit of TB control rather than for their own interests. For instance, a review of the English-language literature published in 2004 identified no mention of TB-specific instruments to measure quality of life (Chang et al., 2004). Since 2004, two studies specifically focused on measures of quality of life in TB patients have been published (Marra et al., 2004; Rajeswari et al., 2005). We also identified an evaluation of how and why TB patients related to and experienced the Penduka TB project in Namibia, conducted through interviews and participants' observations (Augland, 2005). Instruments have been developed to assess patients' empowerment and activation in the management of other chronic conditions (Hibbard et al., 2004).

A good proxy for measuring the effectiveness of an intervention or experience in improving TB patients' well-being is the reduction in stigmatization. An instrument to measure internalized stigma, as a proxy for self-esteem, was developed in Nicaragua (Macq, Solis & Martinez, 2005). In Thailand, where TB is often associated with HIV/AIDS, a TB stigma scale was designed (Sengupta, Pungrassami & Van Rie, 2005), with encouraging characteristics (Cronbach alpha of 0.94 and 0.87 for the two factors identified).

The tools and methods identified for assessing the effects of interventions on patients are summarized in Table 5.

TABLE 5. TOOLS AND METHODS FOR ASSESSING EFFECTS OF INTERVENTIONS ON PATIENTS' LIVES

Reference	Tools and or methods for assessing effect of intervention on "patient's life"
Ngamtrairai & Jittimane (2004)	Measure of self-care behaviour with a 33-item instruments with six sub-scales. Self-care behaviour significantly higher in experimental than in control group.
Getahun (1998); Getahun & Maher (2000); Demissie, Getahun & Lindtjorn (2003)	Qualitative approach used to assess changes provoked by TB clubs on people's attitude towards TB and the perceived effectiveness of the clubs. Focus group discussions and in-depth interviews conducted. Qualitative evaluation showed remarkable changes in patients' understanding of TB, patients' initial reaction to a TB diagnosis, misconceptions about the cause and treatment of TB, social isolation, compliance and belief in modern health care in the TB club area. Community elders, community health agents and local health workers helped TB clubs in referring suspected cases, promoting treatment adherence and tracing defaulters as an integral part of a district TB programme.
Morisky et al. (2001)	Three-item scale to assess medication-taking behaviour and completion of treatment. Peer counselling had significant impact on medication-taking behaviour, which was strongly correlated with completion of care (80.3% in peer counselling group and 77.3% in usual care group completed care).
Johansson & Winkvist (2002)	Qualitative study of issues such as social stigma related to TB and being in charge of the treatment process, which are central issues in empowerment. The central role in the evolution of disease of transparency and trust in the encounter and interactions between health care providers and TB patients are also discussed.
Macq, Solis & Martinez (2006)	Scale designed to assess changes in internal stigma after an intervention, which might be useful as a proxy of patient empowerment.
Wandwallo et al. (2004, 2006)	Qualitative evaluation showed that most patients treated in the community (83%) and in a health facility (79%) were willing to supervise treatment. Most were willing to supervise another TB patient because they had personal experience of the disease (80%) and would like to help another patient. Others (13%) were willing to supervise another patient in order to reduce the burden of TB in the community. A few (7%) were willing to supervise only a family member.
Augland (2005)	In the framework of the Penduka project in Namibia, an extensive qualitative evaluation was conducted with interviews and participant observation at 'DOTS points'. A first round of interviews was conducted, followed by an in-depth interview-guide to interview another group of patients.

---

### **Outcome evaluation: equity**

Particular attention must be paid to the issue of equity in evaluating experiences and interventions for empowering or involving TB patients. On the one hand, many of the reported experiences and interventions specifically targeted poorer and vulnerable groups (Bond, Muchimba & Tihon, 2000; Ngamtrairai & Jittimane, 2004; Sok, Shapiro & Goldfeld, 2004; Franks et al., 2005). On the other hand, strategies to empower TB patients might not follow the 'inverse care law', in which the strongest TB patients are empowered and involved. Bond et al. (2000) noted that care givers, including former TB patients are usually different from the TB patients they visit, being more stable residents, more educated and often people with some standing in their community.

---

The Temeke group of cured TB patients was established in the United Republic of Tanzania as the result of study on involving the local community and former TB patients in treatment support. Mr Mapunde, showing the thumbs-up sign, is the president.



# Conclusions

Empowering and involving TB patients is an increasing source of interest for policy-makers, managers and health care providers involved in TB control. This activity is clearly interconnected with other priorities in TB management, such as equitable access to TB services for vulnerable and poor populations, the interaction between TB and HIV, and human rights. It is, however, complex.

We might have overlooked some documented experiences owing to the inherent weakness of the method used, as many interesting experiences in TB patient empowerment and the involvement of TB patients in DOTS can be found in reports of community-based TB care. Likewise, interventions for empowering TB patients are mentioned in articles reporting interventions to improve adherence. Nevertheless, a number of general conclusions can be drawn.

First, TB patients seldom empower themselves but need the involvement of stakeholders other than the TB programme. These stakeholders might be nongovernmental organizations, activists for persons living with HIV/AIDS and academic institutions.

Secondly, TB patients cannot be empowered by standard, uniform implementation of an intervention. Initial understanding of contextual factors (including stakeholders) and close monitoring of implementation of the intervention are needed.

Thirdly, although various interventions have been evaluated, there have been no comprehensive evaluations of the process or of the results for TB control and for patient empowerment and well-being. Tools and methods to assess some aspects of patient well-being have been used but not yet systematically.

Fourthly, there are probably many more successful small-scale experiences and interventions than have been identified in this review. These should be documented, with their context and process, in order to identify the lessons necessary to scale-up these experiences.

Finally, consideration of patient empowerment should include greater involvement of TB patients themselves. The TB community is far from giving the same voice to TB patients as the community of persons living with HIV/AIDS. Patients' activism, role and effect have not yet been adequately documented and reported.

# Recommendations

---

## **Meaning and purpose of the empowerment of TB patients**

- Clarify the operational definitions of the empowerment and involvement of TB patients in TB control in order to define the objectives of interventions.
- Promote open discussion on the reasons for patient empowerment: only as a cheap labour force for TB control or for more? If empowerment is more than a means for better TB control, it should also be promoted in areas with low TB incidence rates.

---

## **Barriers to the empowerment of TB patients**

- Use participatory methods, such as BEHAVE (de Negri & Karecki, 2004; Child Survival Collaborations and Resources, 2005), to identify barriers to care as a consequence of the organization of health services and TB programmes or perceptions of TB patients in the community.
- Promote pro-poor approaches to assist the most vulnerable TB patients in overcoming barriers to empowerment.
- Tackle the stigmatization of TB, including community awareness.

---

## **Design and choice of strategies to enhance the empowerment of TB patients**

- Use a multifaceted approach rather than a single intervention; for example, adopt the informational–motivational–behaviour model as a frame for implementing education strategies, together with other interventions.
- Implement tailored interventions rather than standardized ones, considering the importance of context: e.g. the strength of the TB programme, the other stakeholders, cultural aspects, the burden of TB and the HIV epidemic.
- Pay special attention to poorer and vulnerable populations to ensure equity in empowerment.
- Analyse the potential and risks of using incentives as part of interventions, to avoid subsequent problems of sustainability.

---

## **Stakeholders**

- Ensure real leadership by patients of patients' empowerment and involvement.
- Explore the potential role of local nongovernmental and community organizations in promoting and strengthening patient empowerment.
- Strengthen the capacity of primary care providers to organize, promote or support the empowerment of TB patients.

---

## **Evaluation and scaling-up**

- Develop and use methods to evaluate the effectiveness of interventions in empowering and involving patients and, ultimately, in improving patient well-being.
- Go beyond experimental evaluation to generate new knowledge from the process and context.
- Avoid blind scaling-up of activities and interventions tested locally.

# Acknowledgements

I am particularly grateful to Ted Torfoss of the Stop TB Partnership secretariat, Haileyesus Getahun of the Stop TB department, WHO for technical support in the design of the project and the writing of the document, and Valérie Diaz of the Stop TB Partnership secretariat for coordinating the publication. This work was financially supported by the Stop TB Partnership secretariat, housed at WHO.

# References

- Akramul I. Community participation in TB control as part of social development: the experience of BRAC. *International Journal of Tuberculosis and Lung Disease*, 2005, 9(11S1):S37.
- Allen S, Dick J. The potential of brief motivational interviewing to enhance tuberculosis care. *International Journal of Tuberculosis and Lung Disease*, 2003, 7(11S1): S190–S191.
- Alvarez Gordillo GdC, Alvarez Gordillo JF, Dorantes Jimenez JE. Educational strategy for improving patient compliance with the tuberculosis treatment regimen in Chiapas, Mexico. *Revista Panamericana De Salud Publica*, 2003, 14:402–408.
- Alvarez-Gordillo GD et al. Perceptions and practices of tuberculosis patients and non-adherence to therapy in Chiapas, Mexico. *Salud Publica de Mexico*, 2000, 42:520–528.
- Asociacion de Enfermos de Tuberculosis. Quien somos? Asociacion de enfermos de tuberculosis 'Victoria Castillo De Canales' [Who are we? Victoria Castillo De Canales association of tuberculosis patients]. <http://www.asetcomas.org.pe/>, 2006.
- Asociacion de Enfermos de Tuberculosis. Experiencias y aportes en la lucha contra la tuberculosis. [Experiences and contributions to the fight against tuberculosis] <http://www.minsa.gob.pe/portal/03Estrategias-Nacionales/04ESN-Tuberculosis/esn-tbcexp.asp>, 2005. Accessed 5 January 2006.
- Atre SR et al. Cultural concepts of tuberculosis and gender among the general population without tuberculosis in rural Maharashtra, India. *Tropical Medicine and International Health*, 2004, 9:1228–1238.
- Augland K. *TB-patient evaluation Penduka TB-training project 2005*. Oslo, Norwegian Association of Heart and Lung Patients, 2005.
- Bam DS et al. A shared responsibility for TB control: DOTS committees succeed in Nepal. *International Journal of Tuberculosis and Lung Disease*, 2004a, 8(11S1): S176.
- Bam DS et al. Success story of tuberculosis control in Nepal. *SAARC Journal of Tuberculosis, Lung Diseases and HIV/AIDS*, 2004b, 1:43–48.
- Banerjee A, Salaniponi F, Harries A. Administration of anti-tuberculosis drugs through patient empowerment. *Tropical Doctor*, 1997, 27:240.
- Bates I et al. Vulnerability to malaria, tuberculosis, and HIV/AIDS infection and disease. Part 1: determinants operating at individual and household level. *Lancet Infectious Diseases*, 2004, 4:267–277.
- Bond VA, Muchimba M, Tihon V. *The care and management of tuberculosis patients by home based care projects in Lusaka Urban*. Lusaka, ZAMBART, Project, 2000.
- Bond VA et al. 'Kuyendela odwala TB'—visiting TB patients: the widening role of home-based care organisations in the management of tuberculosis patients in Lusaka, Zambia. *International Journal of Tuberculosis and Lung Disease*, 2005, 9:282–287.
- Cabrera DM, Morisky DE, Chin S. Development of a tuberculosis education booklet for Latino immigrant patients. *Patient Education and Counseling*, 2002, 46:117–124.
- Campbell M et al. Framework for design and evaluation of complex interventions to improve health. *British Medical Journal*, 2000, 321:694–696.
- Case G. Positively empowered partnerships (PEP), participatory patient involvement in prevention, detection and adherence: new tools in scaling up TB, TB-HIV and TB-MDR care. *International Journal of Tuberculosis and Lung Disease*, 2005, 9(11S1):S46.
- Case G. *The patients' charter for tuberculosis care*. <http://www.worldcarecouncil.org/pdf/PatientsCharterEN2006.pdf>, 2006.
- Cass AD et al. Structured behavioral intervention to increase children's adherence to treatment for latent tuberculosis infection. *International Journal of Tuberculosis and Lung Disease*, 2005, 9:415–420.
- Centers for Disease Control and Prevention. Prevention and control of tuberculosis in US communities with at-risk minority populations: recommendations of the Advisory Council for the Elimination of Tuberculosis and Prevention and control of tuberculosis among homeless persons: recommendations of the Advisory Council for the Elimination of Tuberculosis. *Morbidity and Mortality Weekly Report*, 1992, 41(RR-5):1.
- Centers for Disease Control and Prevention. *TB education and training resources*. <http://www.findtbresources.org/scripts/index.cfm>, 2006.
- Chaisson RE et al. A randomized, controlled trial of interventions to improve adherence to isoniazid therapy to prevent tuberculosis in injection drug users. *American Journal of Medicine*, 2001, 110:610–615.
- Chang B et al. Quality of life in tuberculosis: a review of the English language literature. *Quality of Life Research*, 2004, 13:1633–1642.
- Cheshire L. *TBTV is the greatest thing to happens*. <http://www.tbvtv.org/texts/voices/lucy.cheshire.html>, 2006.
- Child Survival Collaborations and Resources (CORE). *Applying the BEHAVE framework: workshop guide*. [http://www.coregroup.org/working\\_groups/behav\\_guide.cfm](http://www.coregroup.org/working_groups/behav_guide.cfm). 2005.
- Crafton J, Galanowsky K. Striving towards cultural competence. TB and cultural competency: notes from the field, 1-3, [www.umdj.edu/globaltb/downloads/products/newsletter-1.pdf](http://www.umdj.edu/globaltb/downloads/products/newsletter-1.pdf) accessed in 2004.
- Dandona R et al. Utilization of and barriers to public sector tuberculosis services in India. *National Medical Journal of India*, 2004, 17:292–299.

- Datta M, Nichter M. Towards... introducing culturally sensitive tuberculosis education and context specific patient screening. <http://www.tnmmu.ac.in/edu.pdf>. Accessed 30 January 2006.
- Dembele M, Poda G, Dauby C. Developing a patient centred approach in case-management of tuberculosis (TB) patients in Burkina Faso. *International Journal of Tuberculosis and Lung Disease*, 2003, 7(11S1):S128.
- Dembele M et al Sharing decision with tuberculosis patients in health system organisation to offer more 'patient-friendly' care. *International Journal of Tuberculosis and Lung Disease*, 2003, 7:S192.
- Demissie M, Getahun H, Lindtjorn B. Community tuberculosis care through 'TB clubs' in rural north Ethiopia. *Social Science and Medicine*, 2003, 56:2009–2018.
- Dick J, Lombard C. Shared vision—a health education project designed to enhance adherence to anti-tuberculosis treatment. *International Journal of Tuberculosis and Lung Disease*, 1997, 1:181–186.
- Dick J et al. Development of a health education booklet to enhance adherence to tuberculosis treatment. *Tubercle and Lung Disease*, 1996, 77:173–177.
- Dick J et al. Changing professional practice in tuberculosis care: an educational intervention. *Journal of Advanced Nursing*, 2004, 48:434–442.
- Drabo K et al. La décentralisation de la prise en charge des cas de tuberculose; une expérience dans deux districts sanitaires du Burkina Faso. [Decentralization of the management of tuberculosis cases: experience in two health districts in Burkina Faso]. *International Journal of Tuberculosis and Lung Disease*, 2006, 10:93–98.
- Dutton D. Financial, organizational and professional factors affecting health care utilization. *Social Science and Medicine*, 1986, 23:721–735.
- Eastwood SV, Hill PC. A gender-focused qualitative study of barriers to accessing tuberculosis treatment in the Gambia, West Africa. *International Journal of Tuberculosis and Lung Disease*, 2004, 8:70–75.
- El Saadr W. Pathways to completion study. [http://cpmcnet.columbia.edu/dept/harlemtb/innovative\\_programs/pathways\\_info.htm](http://cpmcnet.columbia.edu/dept/harlemtb/innovative_programs/pathways_info.htm), 2006.
- Farmer P. Social scientists and the new tuberculosis. *Social Science and Medicine*, 1997, 44:347–358.
- Feste C, Anderson RM. Empowerment: from philosophy to practice. *Patient Education and Counseling*, 1995, 26:139–144.
- Franks J, Colson P, Hirsch-Moverman Y. *Adherence to treatment for latent tuberculosis infection: a manual for health care providers*. New York, Charles P. Felton National Tuberculosis Center, 2005:1–59.
- Getahun H. Partners against tuberculosis: Ethiopia's 'TB clubs' *Africa Health*, 1998, 21:20.
- Getahun H, Maher D. Contribution of 'TB clubs' to tuberculosis control in a rural district in Ethiopia. *International Journal of Tuberculosis and Lung Disease*, 2000, 4:174–178.
- Gibson N et al. Socio-cultural factors influencing prevention and treatment of tuberculosis in immigrant and aboriginal communities in Canada. *Social Science and Medicine*, 2005, 61:931–942.
- Gie V. Peer workers for adherence to treatment for latent tuberculosis infection: the peer worker perspective. In: 129th Annual Meeting of the American Public Health Association, Washington DC, American Public Health Association, 2001.
- Hampton G. A survivor of Africa's twin epidemics, Winston Zulu pushes for new TB drugs. [http://www.tballiance.org/7\\_5\\_3\\_SmallHomepageFeatureStory.asp](http://www.tballiance.org/7_5_3_SmallHomepageFeatureStory.asp), 2006.
- Harries A et al. 'Community TB care in Africa', a collaborative project coordinated by WHO. Report on a 'lessons learned' meeting in Harare, Zimbabwe, 27–29 September 2000. Geneva, World Health Organization (WHO/CDS/TB/2001.291), 2001.
- He GX et al. Implementing DOTS strategy through tuberculosis clubs. *International Journal of Tuberculosis and Lung Disease*, 2005, 9(11S1):S135–S136.
- Hibbard JH et al. Development of the patient activation measure (PAM): conceptualizing and measuring activation in patients and consumers. *Health Services Research*, 2004, 39:1005–1026.
- Houston HR, Harada N, Makinodan T. Development of a culturally sensitive educational intervention program to reduce the high incidence of tuberculosis among foreign-born Vietnamese. *Ethnicity and Health*, 2002, 7:255–265.
- Hovell MF et al. Increasing Latino adolescents' adherence to treatment for latent tuberculosis infection: a controlled trial. *American Journal of Public Health*, 2003, 93:1871–1877.
- Hurtig AK, Porter JD, Ogden JA. Tuberculosis control and directly observed therapy from the public health/human rights perspective. *International Journal of Tuberculosis and Lung Disease*, 1999, 3:553–560.
- Jaramillo E. *Contribución de la comunidad a la atención de la tuberculosis: una perspectiva Latinoamericana*. [Contribution of the community to detection of tuberculosis: a Latin American contribution], Geneva, World Health Organization (WHO/CDS/TB/2002.304(S)), 2002.
- Johansson E, Winkvist A. Trust and transparency in human encounters in tuberculosis control: lessons learned from Vietnam. *Qualitative Health Research*, 2002, 12:473–491.
- Karim F et al. *Gender barriers to tuberculosis control: Fade-out or in? Key findings and recommendations from the preliminary analysis*. Dhaka, BRAC Centre, 2003.
- Kironde S, Klaasen S. What motivates lay volunteers in high burden but resource-limited tuberculosis control programmes? Perceptions from the Northern Cape Province, South Africa. *International Journal of Tuberculosis and Lung Disease*, 2002, 6:104–110.
- Lawn SD. Tuberculosis in Ghana: social stigma and compliance with treatment. *International Journal of Tuberculosis and Lung Disease*, 2000, 4:1190–1191.

- Lewin S et al. Staff training and ambulatory tuberculosis treatment outcomes: a cluster randomized controlled trial in South Africa. *Bulletin of the World Health Organization*, 2005, 83:250–259.
- Liefooghe R et al. From their own perspective. A Kenyan community's perception of tuberculosis. *Tropical Medicine and International Health*, 1997, 2:809–821.
- Lienhardt C, Ogden JA. Tuberculosis control in resource-poor countries: have we reached the limits of the universal paradigm? *Tropical Medicine and International Health*, 2004, 9:833–841.
- Macedo CE, Ferreira GE, Castellanos JM. 'White flag' community strategy: social mobilizing to achieve TB control in Mexico. *International Journal of Tuberculosis and Lung Disease*, 2003, 7(11S1):S230–S231.
- Macq J, Solis A, Martinez G. A tuberculosis patient's self applied social stigma assessment instrument to assist front line health worker in customizing care in Nicaragua. *International Journal of Tuberculosis and Lung Disease*, 2005, 11(suppl 1):S147–S148.
- Macq J, Solis A, Martinez G. Assessing stigma of tuberculosis. *Psychology, Health and Medicine Journal*, 2006, 11:346–352.
- Macq JCM et al. An exploration of the concept of directly observed treatment (DOT) for tuberculosis patients: from a uniform to a customised approach. *International Journal of Tuberculosis and Lung Disease*, 2003, 7:103–109.
- Macq J et al. Implementing a package of interventions to reduce the negative effects of TB stigma in five municipalities of Nicaragua. *International Journal of Tuberculosis and Lung Disease*, 2004a, 8(11S1):S89.
- Macq J et al. The cost of medical care and people's health-seeking behaviour before being suspected of tuberculosis in three local health systems of Nicaragua. *International Journal of Tuberculosis and Lung Disease*, 2004b, 6:1330–1336.
- Macq J et al. An exploration of the social stigma of tuberculosis in five 'municipios' of Nicaragua to reflect on local interventions. *Health Policy*, 2005a, 74:205–217.
- Macq J et al. The frontline TB care providers' supportive systems: findings from three experiences in Central America and West Africa. *International Journal of Tuberculosis and Lung Disease*, 2005b, 11(suppl 1):S70–S71.
- Macq J et al. Comparing community involvement in TB care in Nicaragua and Burkina Faso. Presented at the joint meeting of the DOTS expansion, TB/HIV and DOTS-plus working groups of the STOP-TB Partnership, 2005c.
- Maher D et al. Treatment of tuberculosis. *BMJ*, 2003, 327:822–823.
- Manders AJ et al. Can guardians supervise TB treatment as well as health workers? A study on adherence during the intensive phase. *International Journal of Tuberculosis and Lung Disease*, 2001, 5:838–842.
- Marra CA et al. Factors influencing quality of life in patients with active tuberculosis. *Health Quality of Life Outcomes*, 2004, 2:58.
- Martin M et al. Tuberculosis education in an endemic setting: application of participatory methods to video development in The Gambia. *International Journal of Tuberculosis and Lung Disease*, 2005, 9:550–555.
- McGregor S. Role, power and subjective choice. *Patient Education and Counseling*, 2006, 60:5–9.
- Michie S, Miles J, Weinman J. Patient-centeredness in chronic illness: what is it and does it matter? *Patient Education and Counseling*, 2003, 51:197–206.
- Morisky DE et al. Behavioral interventions for the control of tuberculosis among adolescents. *Public Health Reports*, 2001, 116:568–574.
- Mwape W, Hirota M. People living with HIV/AIDS, a living tool adherence. *International Journal of Tuberculosis and Lung Disease*, 2005, 9:S198.
- Myrseth S. The human rights and TB-control. <http://www.lhl.no/internet/lhl/english/article6819.ece?service=print>, 2006.
- Natpratan C. A PLHA support group in northwest Cambodia: MMM in Battambang. *International Journal of Tuberculosis and Lung Disease*, 2005, 9(11S1):S46.
- Needham DM, Godfrey-Faussett P, Poster SD. (1998). Barriers to tuberculosis control in urban Zambia: the economic impact and burden on patients prior to diagnosis. *International Journal of Tuberculosis and Lung Disease*, 1998, 2:811–817.
- Needham DM et al. Patient care seeking barriers and tuberculosis programme reform: a qualitative study. *Health Policy*, 2004, 67:93–106.
- de Negri B, Karecki AE. The client oriented aspect of responding to TB: the BEHAVE framework. *International Journal of Tuberculosis and Lung Disease*, 2004, 8(11S1):S214.
- Ngamtrairai N, Jittimane SX. Effect of supportive-educative nursing intervention on self-care behavior among Thai prisoners diagnosed as having pulmonary tuberculosis. *International Journal of Tuberculosis and Lung Disease*, 2004, 8(11-S1):S174–S175.
- Norwegian Association of Heart and Lung Patients. *Peer work: a self-help approach*. Department of International Cooperation. [http://www.lhl.no/internet/multimedia/archive/00002/Peer\\_work-selfhelp\\_ap\\_2988a.doc](http://www.lhl.no/internet/multimedia/archive/00002/Peer_work-selfhelp_ap_2988a.doc). Accessed 1 March 2003.
- van der Oest C et al. Talking about TB: multicultural diversity and tuberculosis services in Waikato, New Zealand. *New Zealand Medical Journal*, 2005, 118:U1496.
- Ogden J et al. Shifting the paradigm in tuberculosis control: illustrations from India. *International Journal of Tuberculosis and Lung Disease*, 1999, 3:855–861.
- Paton NI et al. Randomized controlled trial of nutritional supplementation in patients with newly diagnosed tuberculosis and wasting. *American Journal of Clinical Nutrition*, 2004, 80:460–465.
- Rajeswari R et al. Perceptions of tuberculosis patients about their physical, mental and social well-being: a field report from south India. *Social Science and Medicine*, 2005, 60:1845–1853.

- Rangan S et al. Tackling tuberculosis in urban areas: experiences from Mumbai city. *Health Administrator*, 2003a, 15:72–79.
- Rangan S et al. The Mumbai experience in building field level partnerships for DOTS implementation. *Tuberculosis*, 2003b, 83:165–172.
- Raye S, Nayak AK, De Munynck AO. Trialogue: an extended dialogue approach in the RNTCP, offers a new direction to build partnership with the community. *International Journal of Tuberculosis and Lung Disease*, 2005, 8: S210–S211.
- Raye S, Nayak AK, Nayak DN. Cured TB patient as DOT providers in Orissa, India: a strategic review and potential explorations for programme enhancement. *International Journal of Tuberculosis and Lung Disease*, 2005, 9(11S1):S122.
- Rosas F. Advocating for the informed involvement of PLWHA in efforts to integrate TB-HIV services in Mexico. *International Journal of Tuberculosis and Lung Disease*, 2005, 9(11S1):S20.
- Salim H et al. Patients' participation in case finding and case holding: experiences of Damian Foundation Bangladesh. *International Journal of Tuberculosis and Lung Disease*, 2003, 7(11S1):S255.
- Sanou A et al. Access and adhering to TB treatment: barriers faced by patients and communities in Burkina Faso. *International Journal of Tuberculosis and Lung Disease*, 2004, 8:1479–1483.
- Sengupta SS, Pungrassami PS, Van Rie AV. Scale development of TB and HIV/AIDS stigma with TB patients in southern Thailand. *International Journal of Tuberculosis and Lung Disease*, 2005, 9:S201.
- Shin S et al. Community-based treatment of multi-drug-resistant tuberculosis in Lima, Peru: 7 years of experience. *Social Science and Medicine*, 2004, 59:1529–1539.
- Siddhi A, Kafle R. Community-based advocacy for increased policy engagement in support of joint TB-HIV programs in Nepal. *International Journal of Tuberculosis and Lung Disease*, 2005, 9(11S1):S20.
- Soares EC, Cesar Cavalcante S. *Uso de incentivos e facilitadores no Programa de DOTS da Cidade do Rio de Janeiro* [Use of incentives and facilitation in the DOTS programme in Rio de Janeiro]. <http://www.msh.org/projects/rpmpplus/3.5.5h.htm> . 2004.
- Sok T, Shapiro AE, Goldfeld AE. Microfinance results in high tuberculosis cure rates and poverty reduction in rural Cambodia. *International Journal of Tuberculosis and Lung Disease*, 2004, 8(11-S1):S175.
- Stop TB Partnership. *Summary note: TB/HIV workshop Stop TB Partners' Forum*, New Delhi. <http://www.stoptb.org/news/archives/iacxv/assets/InfoPack/7GB.pdf>, 2004.
- Stop TB Partnership & WHO. *Community contribution to TB care: practice and policy*. Geneva, World Health Organization (WHO/CDS/TB/2003.312), 2003.
- Stop TB Partnership & WHO. *The global plan to stop TB, 2006–2015*. Geneva, World Health Organization (WHO/HTM/STB/2006.35), 2006.
- Tavora E et al. Civil society mobilization for tuberculosis control in Rio de Janeiro State (RJ), Brazil. *International Journal of Tuberculosis and Lung Disease*, 2004, 8(11S1):S90.
- Torfoss T. Front line health workers (FLHW) can organise and encourage. <http://www.lhl.no/internet/lhl/tb/article15224.ece?service=print>, 2006.
- Treatment Action Group. *Towards a revolution in tuberculosis (TB) prevention, care and treatment. Statement of individuals from communities affected by tuberculosis (TB)*. 36th World Congress on Lung Health, 23 October 2005, Paris, France. <http://www.aidsinfonyc.org/tag/tbhiv/revolutionTB.html>, 2006.
- UNDP. *From involvement to empowerment: people living with HIV/AIDS in Asia Pacific*. Vienna, UNDP, 2004.
- Uplekar M, Rangan S, Ogden J. *Gender and tuberculosis control: towards a strategy for research and action*. Geneva, World Health Organization (WHO/CDS/TB/2000.280), 1999.
- Wallerstein N. *What is the evidence on effectiveness of empowerment to improve health?* Copenhagen, WHO Regional Office for Europe. <http://www.euro.who.int/Document/E88086.pdf>, 2006.
- Wandwalo E et al. Effectiveness of community-based directly observed treatment for tuberculosis in an urban setting in Tanzania: a randomised controlled trial. *International Journal of Tuberculosis and Lung Disease*, 2004, 8:1248–1254.
- Wandwalo E et al. Acceptability of community and health facility-based directly observed treatment of tuberculosis in Tanzanian urban setting. *Health Policy*, 2006 (in press).
- WHO. *A human right approach to TB. Guidelines for social mobilization*. Geneva, World Health Organization (WHO/CDS/STB/2001.9), 2001.
- WHO. *Innovative care for chronic conditions: building blocks for action*. Geneva, World Health Organization (WHO/MNC/CCH/02.01), 2002a.
- WHO. *An expanded DOTS framework for effective tuberculosis control*. Geneva, World Health Organization (WHO/CDS/TB/2002.297), 2002b.
- WHO. *Adherence to long term therapies: evidence for action*. Geneva, World Health Organization. [http://www.who.int/chronic\\_conditions/adherence\\_report.pdf](http://www.who.int/chronic_conditions/adherence_report.pdf). 2003.
- WHO. *TB/HIV research priorities in resource-limited settings: report of an expert consultation*. Geneva, World Health Organization (WHO/HTM/2005.355), 2005a.
- WHO. *Addressing poverty in TB control: options for national TB control programmes*. Geneva, World Health Organization (WHO/HTM/TB/2005.352), 2005b.
- WHO. *Preparing a health care workforce for the 21st century: the challenge for chronic condition*. Geneva, World Health Organization [http://www.who.int/chronic\\_conditions/workforce\\_report/en/](http://www.who.int/chronic_conditions/workforce_report/en/) 2005c.



