Patient Centered Approach Strategy

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The three factsheets included in the package were provided by Transformarte and Management Sciences for Health (MSH).

The design and layout of this booklet and entire package was performed by Tristan Bayly.

Acknowledgements are paid to Maarten van Cleeff and Mariah Mansvelt Beck for their valuable input to the development of the strategy. In addition, a special thank you to Barbara Cohen for editing the final version of the strategy.

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The TB Control Assistance Program (TB CAP) is a USAID funded project executed by a coalition of eight agencies: American Thoracic Society, Centers for Disease Control and Prevention, Family Health International, Japan Anti-Tuberculosis Association, KNCV Tuberculosis Foundation, Management Sciences for Health, The Union and the World Health Organization.

The Global Health Bureau, Office of Health, Infectious Disease and Nutrition (HIDN), United States Agency for International Development (USAID), financially supports this document through TB CAP under the terms of Agreement No. GHS-A-00-05-00019-00. The contents are the responsibility of TB CAP and do not necessarily reflect the views of USAID or the United States Government.

Foreword:

As the global TB community moves toward becoming more patient centered we see the health facility, community and patients coming closer together as partners. Ultimately, the interface between the care provider and patient grows stronger and improves health outcomes.

Applying a patient approach is an important strategy to improve the quality of services from the care provider perspective. However, the needs and perspectives of the patient may not always be the same as the provider. This is why we see the application of a patient centered approach becoming vital to efforts to improve quality of, and ensure universal access to health services. The TB CAP patient centered approach package facilitates the process of involving the patient perspective to make certain that their needs and wishes are taken into consideration. Sometimes this process can have surprising results. For example, a patient may indicate that the waiting time at the TB clinic is less important as long as she receives comprehensive health education about TB. In this case, being informed and knowledgeable about TB and how it is affecting the patient's life is more critical than the practical issues. Improving TB services through a patient centered approach which is based on the needs of the patient, not only results in the empowering of the patient but of the health care provider and policy makers as well. It is a process and a mind-set which allows each to learn more about the other's roles and become equal partners in the fight against TB.

We hope that you enjoy the content of this package and that it provides you with new ideas that contribute to the control of tuberculosis. We also urge you to share your experiences with us at TB CAP:
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Patient Centered Approach Strategy

Introduction:

Patient-centeredness is one of the important underlying principles of the Stop TB Strategy. It demands respect for patients' rights as individuals and as partners in TB care and control. Adopting a patient-centered approach is essential if the global targets of 70% case detection and 85% treatment success rate are to be surpassed and universal access achieved. Patient-centeredness enables partnership between the patient and provider, resulting in the best quality of care that is based on needs and individual experiences for increased treatment adherence and ultimately cure. Although women and girls tend to have more responsibility as care providers in the community, they are often considered "second class" members of that same community. Their roles and responsibilities should also be more of a core focus in TB care and control. In light of existing gender inequalities in most parts of the world, the special needs of women and girls must be specifically targeted within TB strategies. (WHO Women and Health 2009)

Case Study:
An unwed mother with four children has been on TB treatment for six months. The journey to the clinic to collect her TB drugs is long and she cannot afford to take public transportation every day, some days she walks two hours to the clinic and two hours home again. There is a private clinic nearer to her village but there you have to pay for the treatment and at the public clinic they are free. The unwed mother of four still has to wait at least 30 minutes to receive her treatment but she does not mind as she likes the care providers here. They give her lots of information, she is told about TB, the progress she is making and how she can best take care of herself. She only wishes that food assistance was available as well as similar TB services closer to her village.

When patients are empowered they become important participants in supporting TB care and control strategies, including active case finding, social support and advocacy. Thus, TB patients are equal partners in global TB care and control. At the same time, when care providers are empowered and enabled to approach the patient as an expert and equal partner the quality of their care improves significantly. Patient-centeredness is important for TB care and control because it is the point where the top down (traditional) approach meets with the bottom up approach.

To facilitate this process TB CAP has developed a Patient Centred Approach package including five tools and a strategy which can support National TB Programs with implementation of a patient-centred approach; *Revised Patient's Charter, QUOTE TB Light, Practical Guide To Improve Quality TB Patient Care, Tool to Estimate Patient Costs and TB Literacy Toolkit.* Their implementation does not automatically equal patient-centeredness but they do enable TB patients to participate and have their voices heard by TB care and control programs. Several examples of patient-centered TB activities in Afghanistan, Brazil, Malawi and Nigeria are also included in the package. The TB CAP tools and strategy presented in this package can contribute to establishing partnerships through improved communication and igniting the spark towards empowerment and activation of TB patients.

Patient Centeredness Core Values:

- Universal access to care and support
- Consideration for **needs**, **perspectives** and **individual experiences**
- Respect for the **right to be informed** and receive the **best quality of care** based on **individual needs**
- Establishment of **mutual trust** and **partnership** in the patient-care provider relationship
- Create opportunity **to provide input** into and **participate** in the planning and management of own care
- **Empowerment** and **activation** to increase **self efficacy**, **independence** and **involvement** at all levels

(Epstein 2005, Michie 2003 and Patients Charter 2006/2010)

Although current guiding policies and strategies of global TB control and care promote a patient-centered approach, actually putting this approach into practice can be challenging. This is especially true in settings where the bio-medical/public health approach has dominated health care delivery. Applying a patient-centered approach requires a new way of thinking, teaching, providing care, prevention and communication. Making such changes is a process that takes time and effort at all levels.

The TB CAP Patient Centred Approach Package is meant for all stakeholders dealing with TB patients, managers, doctors, nurses, pharmacists, laboratory technicians or social supporters. All have an important role in establishing liaisons with patients.

1) Patient-Centeredness

A patient-centered approach defines the patient as an individual placed at the center of the health care system and interventions. Specifically, this means that the health system and its interventions are designed with respect for the patient's

rights, preferences, values and needs. Through this approach, the patient is treated as a partner rather than just a recipient. The *core values* summarized on the left are guiding principles in applying a patient-centered approach. (Epstein et al 2005 and Mitchie et al 2003)

The origins of patient-centeredness can be traced back to the adoption of the right to health as part of the International Human Rights Declaration in 1948 (Cueto 2004). A patient-centered approach took on more prominence with the endorsement of the Declaration on Primary Health Care at Alma Ata in 1978. At that time, the concept of primary health care was evolving and recognized health care as an essential component of social development. (Mahler 1981). Subsequently, several global health initiatives focusing more on decentralization or sector wide approaches have come to the fore. Nevertheless, patients were only taken into account with respect to social justice.

It is only since the 1990s, and in most part as a result of the community led movement in reaction to the HIV and AIDS epidemic, that the importance of applying a patient-centered approach has grown. While good patient-provider communication remains essential, the idea of patients actively involved in the planning and management of their own care is taking precedence. Experience shows that the demand of patients and communities to become more involved at all levels of health care—development of policy, health interventions, prevention and education efforts - has led to new partnerships, increased self efficacy and better health outcomes. (Mitchie et al 2005, Macq et al 2007 and IAPO 2006) Moreover, the GIPA (Greater Involvement of People living with HIV and AIDS) Principle formalized this philosophy in 1994, which in turn has become a catalyst for the treatment of other diseases like TB to become more patient-centered. (Stephens 2004 and UNAIDS 2007)

2) Patient Centeredness in Global TB Care and Control

Historically, TB control is based on a bio-medical and public health approach. TB care and control are organized and implemented by National TB Programs with the goals guided by the Global TB targets. The basic principle of TB care and control is the DOTS Strategy[1] with early diagnosis and treatment adherence being two of the most important elements. In practice, TB patients initiate diagnosis through a visit to a health facility—passive case finding. Treatment is then provided daily at the facility as observed by a nurse or health care worker. Monitoring and evaluation of progress is led by the NTP and rarely involves those affected by TB-patients and communities.

1 DOTS was first defined in 1994. Based on the success of DOTS, WHO expanded the strategy in 2006—the STOP TB Strategy.

During the last five years, patient-centeredness has taken on more precedence within the global TB community. A patient-centered approach is an underlying principle of the Stop TB Strategy as illustrated by component five—Empower People with TB and Communities. The Global Plan to Stop TB further underscores the empowerment of patients to participate in TB control and care activities. (Stop TB Strategy 2006 and Global Plan to Stop TB 2006)

A patient-centered approach is now considered one of the best practices in providing TB and MDR TB treatment as it enhances treatment adherence. Standard 9 of the International Standards for TB Control and Care (ISTC) describes a patient-centered approach as the core element of all TB control and care efforts. For example, health care providers can develop individualized treatment support packages in partnership with patients that address their personal situation (Hopewell et al). The updated guidelines for Programmatic Management of Drug-resistant Tuberculosis (PMDT) have also adopted the patient-centered approach as a key strategy for care and treatment management. (Hopewell et al 2006 and WHO PMDT Guidelines 2008)

These new core elements of TB control and care efforts are further supported by the recognition of patient's rights and responsibilities as described in *The Patient's Charter for TB Care and Control* published in 2006. This document is the first of its kind to specifically outline TB Patients rights and responsibilities. The Patient's Charter provides a backdrop from which all patients can demand information, quality services and participation whilst also guiding their role within TB care and control. In addition, the Patient's Charter is an important tool to facilitate continued learning and understanding of these rights and responsibilities among health care providers and policy makers. The Charter ultimately serves as a vehicle to build partnerships between patients, communities, health care providers and the TB program. (Patient's Charter 2006/2010)

TB CAP Patient Centeredness Strategy: 5 Key Areas

1. **Engage all Stakeholders**
2. **Recognize Patient Rights**
3. **Enable Partnerships**
4. **Empower and Activate Patients and Communities**
5. **Monitor and Document**

Component five of the Stop TB Strategy, empower people with TB and communities, promotes patient-centeredness at several levels of TB care and control programs. Community Based TB Care (CBTC) is considered to be one of the most patient-

centered approaches to date in terms of involvement, empowerment and partnership. Implemented since the 1970s, CBTC has evolved into an initiative that includes the community at a greater level than just observing treatment. As described in the WHO document; Community Involvement in Tuberculosis Care and Prevention (2008), meaningful CBTC creates strong partnerships between the National TB Program (NTP), health care providers, TB patients and the community. These initiatives are based on a strategy that addresses the needs of individuals in the community by involving community members and those affected by TB in the design and implementation of TB care initiatives. CBTC contributes to increased case detection and positive treatment outcome rates through active case finding, educating the community about TB, bringing services closer to the community and empowering the community to support TB care and control activities.

A major component of HIV and AIDS interventions, appreciation for advocacy communication and social mobilization (ACSM) has increased significantly over the last five years. The development of ACSM strategic plans and establishing National Stop TB Partnerships with TB patient representation has increased. Most of the focus in these plans is on communication and social mobilization activities with the main goals of providing information, increasing knowledge of TB and available services and reducing stigma. At present, there is growing involvement of (ex) TB patients at various levels - national and local. They are playing an important role in demanding better quality services, participating in educating communities on TB, as well as providing care and support to other TB patients. (WHO: ACSM for TB Control 2008)

3) TB CAP strategy and tools for Patient Centeredness

TB CAP recognizes the significant affect patient-centeredness has on achieving universal access to TB care and support. In response, a strategy and five tools have been developed to support the implementation and scale-up of a patient-centered approach at the country level.

TB CAP's Patient Centered Strategy:

Patient-centeredness is not a "one size fits all" approach. Depending on the setting, adaptation to local contexts is necessary taking specific knowledge, experience and needs into consideration - particularly those of women and girls. The *core values* introduced above are guiding principles from which a patient-centered approach should be applied. Achieving universal and comprehensive access to TB care and support is the underlying vision. To achieve this vision the scale-up of a patient-

centered approach is necessary at the country level. There are five key areas to take into consideration in the process towards becoming more patient-centered.

A. Engage all Stakeholders: The way in which a patient-centered approach is applied needs to start with understanding how it is defined, understood and experienced by all stakeholders - e.g. NTP, policy makers, health care providers, NGOs, CBOs, patients and communities. During this process there should be a special focus on making sure all voices are heard. In particular, the voices of women and girls deserve special attention as they far too often experience gender-based inequality in terms of accessibility and use of health care services. (WHO: Women and Health 2009)

Applying a patient-centered approach is a shared responsibility. Enabling the full engagement of all stakeholders allows for a framework to be developed that will facilitate how such an approach can best be integrated into program activities, as well as its implications, such as adjusted roles and responsibilities for care providers and patients . It is at this point when benchmarks need to be set with input from all stakeholders to assess the baseline and monitor progress. Moreover, this process allows for full acceptance of applying a patient-centered approach which is owned by all those involved. (Solucion, ACSM working group meeting December 2009)

B. Recognize Patient's Rights: Recognition of patient's rights is at the heart of a patient-centered approach. Working from a rights based approach implies that patients receive and are helped to understand information about TB disease and how it affects their lives. This in turn ensures that they can make informed choices and become equal partners in the management of their care, as well as active advocates in the fight against TB. (Mitchie et al 2005 and Patient's Charter 2006/2010) Moreover, as mentioned above specific attention needs to be given to recognizing gender equality issues. The position of women and girls in many communities is often low and thus their rights are not recognized. (WHO: Women and Health 2009)

The Patient's Charter has been available since 2006 but its implementation is still slow at country level. It is meant to be both actively used and a key tool for applying a patient-centered approach. Moreover, it should be visible at every health facility providing TB care and should be integrated into pre- and in-service training, as well as used as a tool during sessions to educate patients and the community about TB. At the National level, *The Patient's Charter* should be fully integrated into National TB Policies and Strategies.

C. Enable Partnerships: At the health care level, the provider is seen as an expert on TB diagnosis and treatment with an important role in the health care system. The patient is also an expert, but with more emphasis on his or her own needs and experiences. Together these two experts have the potential to make up the perfect health care management team with complementing expertise. As a team, the provider and patient can develop a treatment support package that best fits the patient's personal situation, maximizes ownership by the patient and ultimately, adherence, cure and self-efficacy. (Howe 2006 and Mitchie et al 2005)

As the initiator of providing care, the health care provider has a responsibility to approach the patient both as an equal and as an individual person. On the other hand, the patient has the responsibility to be as open as possible, ask questions and communicate clearly. Effective communication is an important skill, which in some cases needs to be learned. Communication strategies are often integrated in most pre and in-service curricula for health care providers. However, it may be necessary to offer separate trainings for health care personnel on how they can become more patient-centered in their communication—asking personal questions and listening to needs and experiences before making plans and decisions. Building the capacity of the patient and community is also beneficial. In collaboration with patient organizations or NGOs and CBOs, the health care facility can offer communication training

Community-Based Organizations in Nigeria

Partnering with Community-based Organizations (CBOs) is an important strategic approach to empowering and activating TB patients and communities. TB CAP conducted a case study of 12 CBOs in Nigeria that provide TB/HIV services: *Engaging Community-based Organizations in TB/HIV Collaborative Activities*. This document highlights several good practices that reflect the essential role CBOs can have when implementing community-based initiatives. Patient-centered care was often the focus of the CBOs studied, which ranged from providing services in the community to empowering patients to become equal partners in their own care. Due to their position within the community, CBOs are also able to apply gender and cultural sensitive approaches enabling increased equal access and reaching out to all members of the community. Moreover, most of the CBOs participating in the study demonstrated full participation/involvement of patients in line with the GIPA principle—meaningful participation from development, implementation to monitoring and evaluation of programs.

for patients, paying particular attention for women and girls. (IAPO 2007, ISTC 2006 and Mitchie et al 2005)

D. Empower and activate patients and communities: A key element in implementing the full spectrum of patient-centeredness is empowering patients and communities by creating opportunities to gather, discuss and share experiences. Empowerment builds on approaching patients as individuals and involving them as an equal partner in TB care. A TB patient and community that feels empowered will take the opportunity to become engaged in all aspects of TB control, care and support. They will become invaluable partners as their voices will strengthen advocacy efforts by making them relevant and meaningful. Their knowledge and expertise will strengthen interventions—community mobilization and program design - to ensure that messages are appropriate, needs are met, mutual trust is built and stigma is reduced. (Macq 2007 and Mitchie et al 2005)

Most importantly, empowered patients can help build the bridge to reach the most vulnerable patients. The feeling of partnership and mutual trust will be transferred to other members of communities and encourage improved health seeking behavior.

Empowering providers is also an important part of becoming patient-centered. Traditionally, the role of the provider has been to prescribe what they have learned and think to be the best for the patient. Applying a patient-centered approach will result in a shift of these traditional roles but it does not mean that the provider's role becomes less important. Specific effort should be made to ensure that care providers are empowered and enabled to approach the patient as an expert and equal partner. The result will be visible as the quality of their care improves significantly.

E. Monitor and Document: There are many models available to monitor activities and new approaches that can be used when applying a patient-centered approach. (Van der Kwaak A, Dieleman M. 2010.) However, monitoring activities do need to be done more comprehensively than before. A participative approach should be applied by actively involving the patient and communities. For example, patients and communities need to be included in the planning process when bench marks and targets are set—see key area A: *Engaging all Stakeholders*. Patients, communities and providers should be involved in the data collection process, such as through the establishment of patient task forces with the objective to assess the baseline situation, test quality of policies and services against the *Patient Centeredness Core Values* and benchmarks. In addition, qualitative methods

can be applied like observation, skills check lists, focus group discussions and implementation of self-assessment procedures.

TB CAP Tools and Experiences:

In support of the TB CAP Patient-centered strategy, five tools have been developed: *QUOTE TB Light, Practical Guide to Improve Quality TB Patient Care, Tool to Estimate Patients' Costs, TB Literacy Toolkit* and *The Patient's Charter.* Each tool contains practical approaches to increase quality of services, equitable access and knowledge of TB care that can be easily implemented by NTPs in partnership with Health Care Providers, NGOs, CSOs, Universities and most importantly patients and the community. TB CAP acknowledges that the tools included in this package may not fully meet the *Patient Centeredness Core Values*. However, they do make important contributions towards becoming more patient-centered.

QUOTE TB Light:

As recipients of services, TB patients are considered to be one of the important expert groups to assess the quality of those services. The perspective of patients with respect to the care they receive are therefore an important element to improving services to better meet their needs, increase equity and improve access to services for diagnosis and treatment.

QUOTE TB Light is a management tool to help National TB Programs assess the quality of TB services through the eyes of the patient. The results of assessment give a clear indication of the issues that need to be addressed and can be used to develop interventions and set bench marks for improving TB services. *QUOTE TB Light* is unique because TB patients are involved in all stages of its application. Involving patients in the improvement process contributes to the empowerment of TB patients and their communities, as underscored in the *Patient Charter for TB Control* and Care.

Practical Guide to Improve Quality TB Patient Care:

As providers of TB care it is important too, that they are empowered to become more patient-centered. To help facilitate this process the Evidence-based Participatory Quality Improvement (EPQI) methodology has been adapted to TB and field tested in Mexico with positive results. It is an innovative way to obtain better results, with the commitment of those who are directly responsible for patient care.

Tool to Estimate Patients' Costs:

For TB patients, there are many barriers to accessing services and they can be especially detrimental for vulnerable groups—both economically and socially. One of the most important barriers is the indirect costs in terms of transportation, food and loss of income. The *Tool to Estimate Patient's Costs* was developed to help National TB Programs understand the costs that are borne by patients before and during diagnosis and treatment.

The tool is applied as an operational research project by conducting interviews with TB patients using a standardized questionnaire. Based on the results, NTPs are able to 1) identify the economic constraints individuals and families experience; 2) assess the "impoverishing" effect of TB on patients and their families and 3) establish an evidence base for potential interventions to improve equity in access to care. Ultimately, this tool will support NTPs to develop and implement interventions to reduce the barriers and reasons for delay many patients experience to seek timely diagnosis and treatment.

Case Study:

A young banker just finishing his TB treatment recalls his experience that started out with challenges but ended with him being able to complete his treatment. A good TB programme is that which is accurate in terms of diagnosis, with proper treatment, commitment on the part of the patient, availability of drugs and their freeness. It is also important that such a programme is easily accessible to the patient.

From the beginning of his treatment the young banker is well versed in TB as his brother had died of it several years ago. However, he still had to undergo several months of visits to different providers, and payments of services, before he could get the proper diagnosis of TB. Once finally able to start treatment the challenges continue with bureaucratic glitches when transferred to a clinic nearby his home to not receiving enough information about his treatment, such as follow-up sputum tests and the possible side effects of the TB drugs. The care providers in the clinic also did not seem to have a good attitude towards the patients, they treated the young banker as if he was going to infect them. In the end, he feels lucky that he is able to demand some information, and care, as well as the self will to continue his treatment until finished.

TB Literacy Toolkit:

Health education is a critical component of a patient-centered approach. Understanding an illness and how it affects ones life, as well as the options that are available for treatment

are necessary for a patient and community to take an active role. Knowledge that is owned by a patient can also be transferred to others in the community. The *TB Treatment Literacy Toolkit* was developed to support health care providers, educators, outreach workers and supervisors in their efforts to increase awareness on TB, counseling and treatment of TB among those living with HIV and what it takes to complete treatment. The theme of the toolkit "Within Our Reach—Stopping TB Together," captures the idea that it takes all stakeholders to support TB control and treatment. The toolkit also aims to increase patient confidence in completion of treatment and cure, educate caregivers and reduce stigma. The toolkit consists of several TB education aides, videos, flipcharts and brochures, which can be used in different settings. For example, individual sessions can be conducted with the flipcharts between the provider and patient and the video can be played in a waiting area of a health facility or during a community education event.

Patient's Charter and Rights and Responsibilities Roadshows:

As part of an interactive exercise with TB patients around the world, the *Patient's Charter* was updated and revised to include additional information on X/MDR-TB, Infection Control, Quality Assurance and patient responsibilities. To scale-up implementation of the *Patient's Charter* at the country level, TB CAP supported "Rights and Responsibilities" Roadshows in two countries; DR Congo and Indonesia. The roadshows are meant to join the rights based approach with the individual duty of those affected by TB to act responsibly in face of a public health threat. The ultimate goal is to enable patients and communities to partner with care providers and programs, as well as working together on a rights-based approach to scaling up services. (World Care Council Website: http://worldcarecouncil.org/)

The road shows consist of two one day advocacy meetings held consecutively; one specifically focused on patients and communities and the other focused on the National TB Program and other stakeholders. The objectives of the workshops include: 1) Raise awareness of Rights and Responsibilities, and mobilize a partnership between community and health professionals; 2) Forge local tools for outreach, present existing 'helpers' and produce a draft Action Plan to drive forward implementation of Rights and Responsibilities policies; 3) Present Action Plan, advocate for mutually beneficial collaboration, and secure agreements 'in principle' with both public and private health providers and 4) Engage the media and other communication services in the outreach on Rights and Responsibilities, in the interest of the country. (World Care Council Website: http://worldcarecouncil.org/)

Conclusion

Applying a patient-centered approach is essential to improved TB care and control. Patient-centeredness has become a central focus to global TB policies and guidelines and its application is an important strategy towards reaching universal access for all TB patients. The urgency to scale-up patient-centeredness at the country level is growing. TB CAP's response is described within this document including a strategy supported by five tools that will help countries take the next steps towards becoming patient-centered. While these tools are an important aid, the real challenge lies in a much needed paradigm shift at levels—policies, TB program management, healthcare workers and the community. Becoming patient-centered is not achieved simply by applying a tool; it is a new way of thinking and working. Patient-centeredness will not occur instantly, it is a process that needs to be piloted, monitored and documented. It is an approach that can and needs to be adopted, and the TB CAP patient-centered package provides a practical way to start.

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