TB CARE I

PATIENT CENTERED APPROACH

Providing patient-centered care is crucial to achieving universal access to quality TB services for all people.

TB CARE I responded to this need with the patient-centered approach package, read about it in detail within.

Above - Patient Interview to Assess Quality of Care, Cambodia
Below - MDR-TB Out-Patient Clinic, Indonesia - Photo: Jan Voskens

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TB CARE I

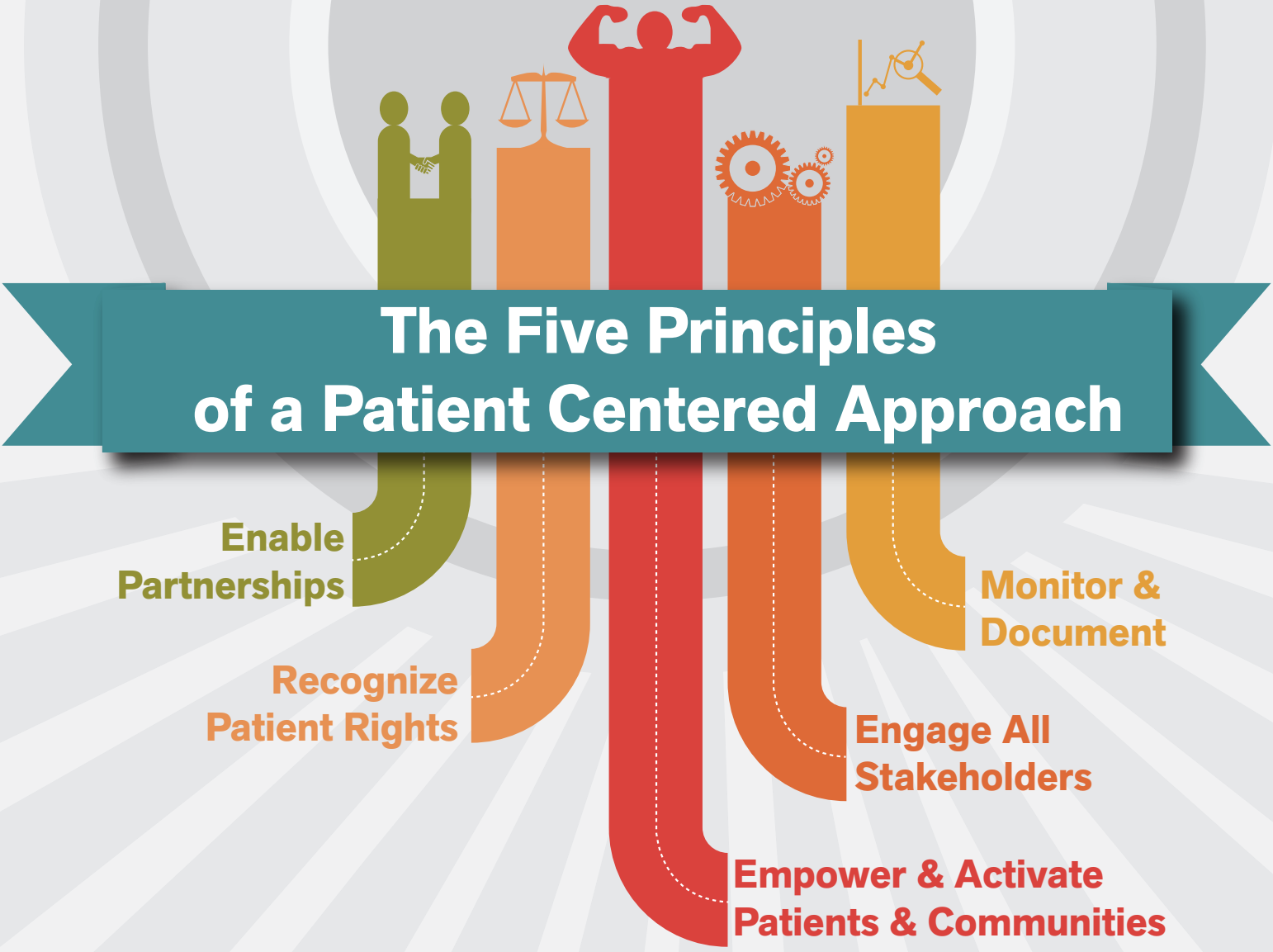
THE NEED

What is a patient-centered approach and why is it important to tuberculosis control?

Patient-centered care is an important underlying principle of quality health care systems and interventions. The Institute of Medicine defines patient-centered care as "Providing care that is respectful of and responsive to individual patient preferences, needs, and values, and ensuring that patient values guide all clinical decisions."

Within the context of tuberculosis (TB), patient-centered care respects an individual's right to participate actively as an informed partner in decisions and activities related to TB diagnosis and treatment. Patient-centered care forms an integral part of the first pillar of the new global post-2015 TB strategy, and 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."

Although current policies and strategies for global TB control promote a patient-centered approach (PCA), actually putting this approach into practice can be challenging. Applying a PCA requires a new way of thinking, teaching, communicating, and delivering services. TB control programs and their partners need easy-to-use tools that can help adapt the concept of patient-centered care to their own local context. As part of its USAID-funded work, TB CARE I set out to create a package of PCA tools to facilitate this process.



MDR-TB Patient Supported by his Community DOTS Provider, Nigeria

TB CARE I RESPONSE

TB CARE I partners developed a number of tools for national programs and local partners to complement existing documents and facilitate implementation of a PCA to TB control. The PCA package includes five tools that can be used individually or in combination, to address specific country needs: *Patients' Charter for Tuberculosis Care*, *QUOTE TB Light*, *Tool to Estimate Patients' Costs*, *TB/HIV Literacy Toolkit* and *Practical Guide to Improve Quality TB Patient Care*. Each tool's purpose and use is described on the next page.

The tools were piloted in collaboration with the national TB programs in five countries: Cambodia, Indonesia, Mozambique, Nigeria and Zambia.

The project included four major activities:

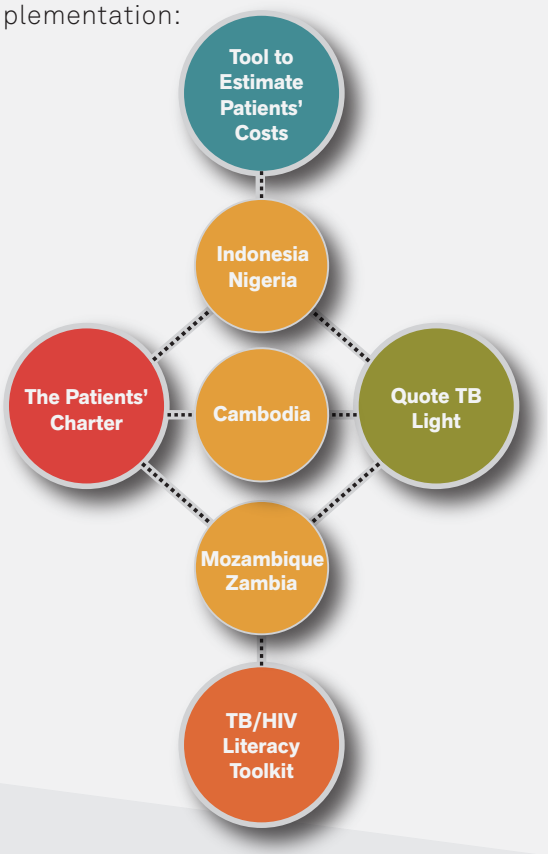
1. Two regional workshops to kick off the project, introduce the concept of a PCA, provide an orientation to the five tools in the package, and develop work plans.

2. PCA tool implementation in two districts in each country for a period of 6-8 months.

3. A before-and-after study in the two pilot districts and one control (non-intervention) district per country to measure change and learn what worked, what did not work, and why.

4. One end-of-project workshop to discuss experiences, lessons learned, results and recommendations.

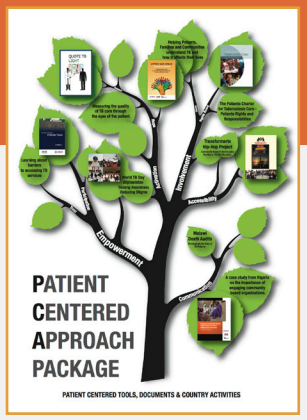
Each country selected two or three tools for pilot implementation:



Country teams were established including a TB CARE I focal point, National TB Program (NTP) representatives, research institute or university and civil society or TB patient representatives.

The teams participated in regional kick-off workshops to select the tools and develop implementation work plans. During implementation, only selected members of the team participated actively — mostly the NTP, research institutes and TB CARE I focal points.

THE PACKAGE



Below are brief descriptions of the five tools included in the PCA package, including what they are, how they can be used, and the intended users.

The Patients' Charter for Tuberculosis Care (The Charter):

What? The Charter was developed by the World Care Council as a companion document to the *International Standards of TB Care*. The Charter outlines TB patients' rights and responsibilities in understandable language. It provides a foundation from which all patients and their care-givers can demand information, quality services and participation while also guiding their role within TB care and control.

How? Use the Charter as a health empowerment tool for individual patients and patient groups, community mobilization and advocacy. You can also use it to educate providers and improve their understanding of patients' rights. It is most effective when dialogue is achieved among patients and with HCWs or other stakeholders. Translated versions of the Charter can be developed and printed as brochures and posters for distribution at health facilities and within communities.

Who? Patients, community volunteers, civil society organizations (CSOs), and health care workers (HCWs).

TB/HIV Literacy Toolkit:

What? The toolkit consists of educational materials on TB and HIV. It includes table-top flip charts and videos with 'The Story of Thomas' as well as brochures on TB and HIV. The stories specifically address basic facts on TB and TB/HIV, prevention methods, the importance of adherence to treatment, and misconceptions in the community that contribute to fear and stigma.

How? You can use the toolkit to support health education sessions for individual patients, caregivers, or the wider public to increase awareness of TB and HIV co-infection, reduce stigma, and promote positive behavior change at individual and community levels.

Who? HCWs, community volunteers and CSOs.

QUOTE TB Light:

What? QUOTE TB Light is a management tool to help NTPs, health facilities, and their partners assess the quality of TB services from a patient perspective. The tool focuses on nine dimensions of quality TB care. It consists of a TB patient focus group discussion guide, standardized TB patient questionnaire, and quality impact scoring sheet. The results provide a clear indication of issues that need to be addressed and can be used to develop interventions and set bench marks for improving TB services.

How? You can implement the tool in three steps:
1) Conducting focus group discussions with TB patients to rank the quality dimensions based on their relative importance to patients;
2) Administering a standardized questionnaire to individual TB patients to assess health facility performance; and
3) Calculating a final quality impact score.

Who? National TB program staff, facility managers, CSOs and operations research groups or academic institutions.

Tool to Estimate Patients' Costs:

What? This tool consists of a standardized questionnaire for patients to help national TB programs, facilities, and project implementers estimate the costs incurred by patients and their families while seeking TB diagnosis and completing treatment.

How? You can apply the tool as an operations research study with individual patient interviews using the standardized questionnaire.

Who? NTP staff, technical partners, operations research groups and academic institutions

Practical Guide to Improve Quality TB Patient Care:

What? The guide consists of self-assessment tools to help HCWs improve their skills in applying a PCA. The tool is based on the Evidence-based Participatory Quality Improvement (EPQI) methodology, which has been adapted to TB and field-tested in Mexico with positive results.

How? You can introduce the self-assessment as part of HCW trainings (pre-service and in-service), use it to stimulate discussions during supportive supervision visits or in individual HCW performance assessment processes, or provide it directly to individual HCWs, to use on their own.

Who? HCWs, facility managers, and trainers

The PCA package is meant to provide a comprehensive approach to improving patient-centered care, but each tool can also be used as a stand-alone document. Countries and implementers can choose to use all of the tools, or only the ones that are most relevant to their context.

Focus Group Discussion using Patient Centered Approach Tools, Indonesia - Photo: Nana Widiestu

COUNTRY EXPERIENCES

Indonesia: Joint implementation of The Patients' Charter and QUOTE TB Light

The Indonesia TB program was an early adopter of The Charter. Its use was integrated into the National TB Guidelines and the document was translated into Bahasa Indonesia, the official national language, in 2006. However, awareness of The Charter remained very low among TB patients and the community. Based on this experience, the country team developed a methodology that would maximize visibility of The Charter and enable dialogue between patients and HCWs. They used the unique approach of combining the introduction of The Charter with a discussion of the results from the use of the *QUOTE TB Light* tool.

An illustrated Patients' Charter brochure was developed and banners were placed in the waiting areas of health facilities participating in the PCA pilot. Workshops to introduce The Charter together with the *International Standards for TB Care* (ISTC - the standards document for TB providers) were organized in collaboration with local patient support groups. Both HCWs and patients were invited to participate in the workshops. Results from *QUOTE TB Light* were presented to create a setting in which quality issues could be discussed from the patient perspective. The Charter provided the framework for discussing key issues needing attention. The workshop enabled links to be made between the *QUOTE TB Light* results, The Charter and the ISTC. This mixed approach created an opportunity for open dialogue between patients and HCWs and created a platform for developing a mutual understanding and appreciation of each other's roles and experiences, encouraging partnership.

By the end of the pilot, awareness of The Charter among TB patients increased from 3.2% to 32.1%. TB patients commented that once they learned of their rights as stated in The Charter, they participated more actively and started to express themselves more freely—they saw The Charter as a powerful tool. *QUOTE TB Light* provided important insights to HCWs regarding the quality of services from the patient perspective. The tool showed that patient-provider interaction and professional competence were the two most important quality dimensions in need of improvement. The health care facilities participating in the pilot took note, and have allotted specific days and times for a "TB clinic" to provide additional counseling for patients.

The positive results of the PCA pilot were shared with the national TB program (NTP), and plans are underway to scale up to other parts of the country. Recently, KNCV/TB CARE I collaborated with the NTP and CSOs to develop PCA standard operating procedures (SOPs) specific to the Indonesian context. The PCA SOPs include guidance on scaling up the use of four PCA tools and defining the roles for implementation and monitoring.

COUNTRY EXPERIENCES

Mozambique: Pairing The Patients' Charter with the TB/HIV Literacy Toolkit

The Mozambique country team chose local community-based organizations (CBOs) to implement the selected PCA tools. Field officers of the CBOs were trained on how to use the tools and supervise pilot activities.

The *TB/HIV Literacy Toolkit* was originally developed in Mozambique by TB CARE I partner FHI 360. The PCA pilot provided the team with an opportunity to expand use of the tool. *The Patients' Charter* was translated into Portuguese and combined with the *TB/HIV Literacy Toolkit* as a health education packet. At health facilities, providers introduced The Charter to TB patients initiating treatment. The *TB/HIV Literacy Toolkit* was used to help patients and their families understand their TB illness and how it would affect their lives. Sessions were conducted individually and in groups at health facilities. At the community level, volunteers used The Charter and *TB/HIV Literacy Toolkit* during health education sessions with small groups and during home-based visits to support TB patients on treatment.

The Charter was unknown to TB patients participating in the before- study assessment. The after-study assessment showed an increase, with more than 20% of TB patients being aware of the Charter.

> "I had seen something on TV about Patient Rights but I never knew it also applied to me; I thought it was only for people in Maputo. I also have rights!"
> Patient in Chibuto District

HCWs found The Charter to be very useful in helping patients understand the importance of adhering to treatment and protecting family members from infection. Health providers also described how, after learning about their rights, patients became more engaged and started to speak up and ask more questions at the health facility.

One patient described how she used The Charter in her home with her family: "I told them that I was sick with TB but still a person that needs support!" (Patient in Chibuto District)

> "I told them that I was sick with TB but still a person that needs support!"
> Patient in Chibuto District

The *TB/HIV Literacy Toolkit* was seen as a valuable health education tool by both HCWs and community volunteers as it covered all necessary information regarding TB/HIV - from the basics of TB and HIV prevention and treatment to traditional beliefs in the community. The tool also provided support for creating dialogue between patients and community members during education sessions. The after-study showed a 32% increase in knowledge of how TB is transmitted, which was partly attributable to implementation of the *TB/HIV Literacy Toolkit*.

QUOTE TB Light was implemented in an abbreviated form by the CBOs, who did not have the capacity to implement all three steps of the tool. They used only the focus group discussions with patients to rank the importance of the nine quality dimensions, including a discussion of service gaps. The results were found to be very useful at the community/facility level and contributed to planning of community-based DOTS activities while ensuring service gaps identified were addressed at facility level.

Implementation of both The Charter and the *TB/HIV Literacy Toolkit* have been scaled up to an additional 25 districts. There are also plans to revise The Charter with illustrations to improve accessibility.

Patient-Centered Approach Data Collection Exercise, Zambia - Photo: Steven Bwalya

Patient Centered Approach Focus Group, Cambodia - Photo: Pichenda Koeut

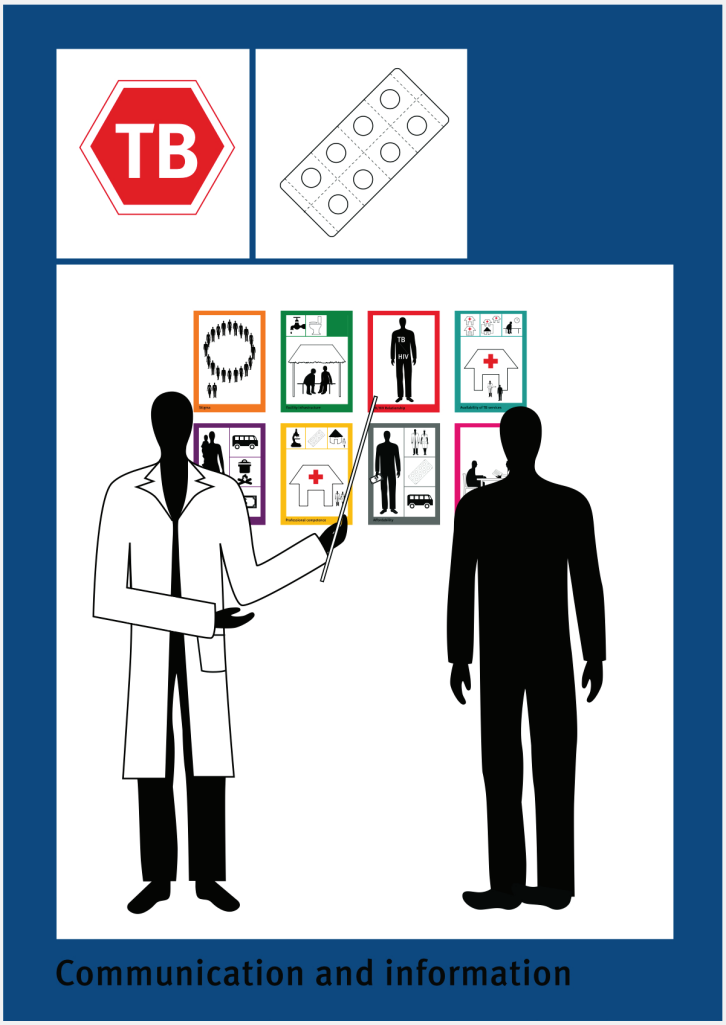
CONCLUSIONS

The PCA pilot demonstrated that with a few practical approaches, TB programs and health facilities can make the first steps to improving patient-centered care. Most tools were found to be easy to implement. Where there were challenges with implementation, particularly with the *Tool to Estimate Patients' Costs*, the tools have been modified to address user concerns.

As a result of the pilot, patients became more aware of their rights and responsibilities, empowering them to demand better services, organize themselves and become involved in TB activities. HCWs gained new insight into the experiences and challenges faced by patients in accessing TB services. They were also provided with new tools to strengthen their important role in providing information and adherence support to TB patients. Several barriers and quality of care issues were identified through the use of the tools, providing each of the countries with an evidence base to develop interventions for PCA improvements based on the patient perspective.

However, use of the tools alone does not guarantee that patient-centered care is fully implemented. Applying a patient-centered approach is an investment in changing health care culture. It involves multiple stakeholders and it takes time. Patient-centered care is a shared responsibility that needs to be defined within each cultural context and and fully integrated into NTPs.

THE TOOLS



How can you use the PCA tools?

The tools are freely accessible to anyone who would like to use them. They may be downloaded from the TB CARE I website: www.tbcare1.org

If you would like technical support to learn about or use the tools, you can contact us via the addresses below.

We would love to hear back from you if you use these tools and have success stories or suggestions for improvements you would like to share with us.

The full range of TB CARE I tools, guidelines, handbooks and reports can be found here: http://www.tbcare1.org/publications.

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What is TB CARE I?

TB CARE I is a USAID five year cooperative agreement (2010-2015) that has been awarded to the Tuberculosis Coalition for Technical Assistance (TBCTA) with KNCV Tuberculosis Foundation as the lead partner.

KNCV To eliminate TB — TUBERCULOSISFOUNDATION

TB CARE I is a unique coalition of the major international organizations in TB control: American Thoracic Society (ATS), FHI 360, International Union Against Tuberculosis and Lung Disease (The Union), Japan Anti-Tuberculosis Association (JATA), KNCV Tuberculosis Foundation, Management Sciences for Health (MSH), World Health Organization (WHO).

TB CARE contributes to three USAID target areas:

- Sustain or exceed 84% case detection rate and 87% treatment success rate
- Treat successfully 2.55 million new sputum-positive TB cases
- Diagnose and treat 57,200 new cases of multi-drug resistant TB (MDR-TB)

By focusing on eight priority technical areas:

- Universal and Early Access
- Laboratories
- Infection Control (IC)
- Programmatic Management of Drug Resistant TB (PMDT)
- TB/HIV
- Health Systems Strengthening
- Monitoring & Evaluation (M&E), Operations Research (OR) and Surveillance
- Drug Supply and Management

And four over-arching elements:

- **C**ollaboration and Coordination
- **A**ccess to TB services for all people
- **R**esponsible and Responsive Management Practices
- **E**vidence based M&E

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