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QUOTE-TB

Measuring the quality of TB
services:
the patient's perspective

Preface

Tuberculosis (TB) currently still affects about 9 million individuals per year and leads to approximately 1.5 million deaths. Although most TB patients can be cured with good treatment within six to eight months, TB can affect a person for a much longer period. Early diagnosis and appropriate treatment are among the cornerstones of the directly observed treatment short course (DOTS) strategy. The targets to control the worldwide TB epidemic, as recognized by the WHO/Stop TB Partnership and included in the Millennium Development Goals (MDGs), are to diagnose at least 70% of infectious TB cases and successfully treat at least 85% of these.

Patient satisfaction and the wider concept of responsiveness and quality of the health service as seen through the eyes of the patient are decisive factors for delays in diagnosis and compromised adherence to treatment, resulting in prolonged transmission of infection in the community, development of drug resistance and increased tuberculosis mortality.

However, TB patients' perspectives have been missing from the original DOTS strategy. If there are studies on patients' perspectives, the results have not been used to improve TB programmes.

Therefore, effective and simple tools are needed to assess the technical and interpersonal aspects of the quality of services at the interface between health staff and patient. QUOTE-TB is just such a standardized tool for patient interviews, which capture patient perspectives and which can be used by National TB Programme staff to improve the quality of TB services and stay accountable to TB patients.

QUOTE-TB consists of two questionnaires, one to measure the performance, and one to measure the importance of quality aspects of TB services, as seen through the eyes of the patients. The combined score informs the NTP manager how the health services is performing,

This book consists of two parts: the first part focuses on the practical use of QUOTE-TB in East African countries or similar settings. The second is a guide on how to develop or adapt the tool to other settings. The target audience is National TB Programme managers, TB staff, TB consultants and any manager or researcher interested in quality of care and patient perspectives.

QUOTE-TB is a co production being developed by staff from the Regional Centre for Quality Health Care (RCHQHC) in Kampala, the Royal Tropical Institute (KIT) in Amsterdam, The Netherlands Institute for Health Services Research (NIVEL) in Utrecht and the KNCV Tuberculosis Foundation in The Hague.

We hope that this tool will contribute to a better insight and better interface between tuberculosis patients and their health care providers

Dr. Maarten van Cleeff, Director TBCTA

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QUOTE-TB was developed through operational research in a number of workshops and fieldwork during 2004 to 2006. In 2007, this final Guide was written, after several times being shared and discussed with all stakeholders, including State of The Art meetings conducted by the Regional Centre of Quality Health Care in Uganda.

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Abbreviations

ACSM	Advocacy, Communication and Social Mobilization
CAHPS	Consumer Assessment of Health Plan Surveys
CB-DOTS	Community-based DOTS
DOTS	Directly Observed Treatment Short Course
DTLS	District Tuberculosis and Leprosy Supervisor
EQA	External Quality Assurance
HUMC	Health Unit Management Committee
KIT	Royal Tropical Institute
KNCV	Royal Netherlands Tuberculosis Association
MDG	Millennium Development Goal
MDR	Multi-drug Resistance
NIVEL	Netherlands Institute for Health Services Research
NL	The Netherlands
NT(L)P	National Tuberculosis (and Leprosy) Programme
NTP	National TB Programme
MOH	Ministry of Health
NGO	Non-government Organization
PIA	Performance Improvement Approach
PPP	Public/Private Partnerships
QUOTE	Quality of Care as seen through the Eyes of the Patient
RCQHC	Regional Centre for Quality of Health Care
QI	Quality Impact (or Quality Improvement)
TB	Tuberculosis
TBTCA	Tuberculosis Coalition for Technical Assistance
TH	Traditional Healer
UK	United Kingdom
WHO	World Health Organization

Glossary

Case mix adjuster	Variable used to adjust for differences in respondents or facilities, so that meaningful comparison can be made
Cronbach's alpha	Measure of the consistency between questions, or the reliability of the questions for measuring the same concept
Defaulter	A patient who interrupts treatment or is not compliant with treatment
Dimension.....	Broad title of a group of conceptually similar items
Factor analysis	Detection of any hidden hypothetical variables, either for explorative reasons or for reduction of a large number of variables into a limited number of dimensions, by identifying 'unreliable' items, with little in common with other items, and 'invalid' items that do not discriminate between factors
Focus group discussion	A group discussion of approximately 6–12 persons guided by a facilitator, during which group members talk freely and spontaneously about a certain topic. A focus group discussion is a qualitative method to obtain in-depth information on the concepts, perceptions and ideas of a group
Importance score.....	Score of the ranking or rating of items or dimensions perceived as extremely important. A practical way to score importance is to count the percentage of respondents rating an item extremely important
In-depth interview	An open-ended, discovery-oriented method that is well suited for describing both programme processes and outcomes from the perspective of the target audience or key stakeholders. The goal is to deeply explore the respondent's point of view, feelings and perspectives

Item.....	A question in a questionnaire belonging to a certain dimension, highlighting a certain aspect of that dimension
Likert scale	The most widely used scale in survey research. It is a response scale often used in questionnaires. When responding to a Likert questionnaire item, respondents specify their level of agreement to a statement
Performance score	Score of the rating of items, where the performance of health services is perceived as negative. A practical way to score performance is to count the percentage of respondents having a negative report on performance
Psychometric testing	Testing of the reliability and the validity of a questionnaire
Quality impact score.....	Product of importance and performance scores, whereby the importance scores are weighing factors for the performance score
Reliability.....	Extent to which a result of a measurement corresponds with reality
Scalability	The extent to which a group of variables together form a reliable entity, so that they score consistently on a (Likert) scale
Skewness	Departure from a normal distribution
Taxonomy.....	Structure of a questionnaire of dimensions and items or aspects
Topic guide	A check list with the main topics for focus group discussions or interviews. It helps to keep track of the research objectives while at the same time giving flexibility for emergence of insights
Triangulation	A process used to validate the data obtained in a study, usually involving alternative data sources or collection processes to corroborate data
Validation	Process of exploring questions to determine whether they really measure what they are supposed to measure

Varimax rotation..... Rotation of the axes of factors to maximize the variance (variability) of the 'new' variable (factor), while minimizing the variance around the new variable

Executive summary

What is QUOTE-TB?

QUOTE-TB is an instrument to measure the quality of services as perceived by tuberculosis (TB) patients. QUOTE is an acronym for Quality of Care as seen through the Eyes of the Patient. QUOTE-TB consists of two questionnaires: one to measure the performance of TB services (routinely) and one to measure importance (once every five years). The combination of the two scores measures the quality of TB services.

The two instruments need to be used to combine the scores of these interviews to calculate a quality impact (QI) index. The essence is that the importance scores are used as weighing factors for performance scores.

The tool is unique because TB patients are involved in all stages of its development, and the information obtained by using the tool adds the patient's perspective to measuring quality in TB control. Involving patients in the improvement process will contribute to the empowerment of TB patients and their communities.

QUOTE-TB is also contextually specific. It has been developed for an East African context and will need to be adapted for other contexts. East African patients may find certain aspects of TB services more important than, for example, patients in Europe or South-East Asia. Moreover, importance – even in the same context – may change over time.

This guide consists of two volumes: one explains how to use QUOTE-TB, and a second explains how to develop it or adapt it to other countries.

VOLUME 1: GUIDE TO USING QUOTE-TB

Using QUOTE-TB on three levels

QUOTE-TB can be used as an instrument for quality improvement at national, district and facility level.

Interviews of TB patients take place at facility level. These can be public or private facilities. Also, defaulters could be traced and interviewed, as they have their own expectations and experiences of the health services. An example of how to calculate performance and quality impact scores is provided.

At national level the tool provides a standardized method to measure quality of care from the perspective of TB patients in external reviews of the

National TB Programme (NTP). Also, it can be used for internal ongoing monitoring of NTP performance and for benchmarking: it provides the NTP with a nationwide view on quality of care and discloses quality differences between districts and between facilities within districts.

At district level the tool allows analysis of all reviewed health facilities and benchmarking at the district level by providing an overall view of quality of care by district and of differences between health facilities.

At health facility level QUOTE-TB and its methodology can be used in facilities with more than 50 TB patients. In facilities with fewer than 50 TB patients the performance part of the tool can be used as a patient exit interview to reveal performance gaps. The picture cards can be useful in focus group discussions to discuss and improve services at facility level.

Adaptation of QUOTE-TB to use in countries with different TB epidemiology and/or different cultural and other socio-economic settings is described.

In the annexes of this section, the performance and importance questionnaires are provided, as well as how to use picture cards for discussions and ranking.

VOLUME 2. GUIDE TO DEVELOPING AND ADAPTING QUOTE-TB

A short description of developing QUOTE-TB in six steps

QUOTE-TB was developed by three research teams from Malawi, Kenya and Uganda. These three East African countries were chosen because of their cultural and socio-economic similarities, and to capture as many general importance issues as possible.

The first part entailed qualitative research and consisted of a first workshop to familiarize team members with qualitative research techniques, preparation of study protocol, and the actual fieldwork, whereby the importance dimensions were established in focus group discussions and in-depth interviews with TB patients. In a second workshop the transcripts of the data were analysed and a first draft of QUOTE-TB was designed.

Thereafter, a third workshop was held to fine-tune the tools, familiarize the research teams with ranking and rating procedures and prepare for field testing. The new QUOTE-TB importance and performance tools were tested in the field by interviewing over 300 TB patients in three countries. The data from the questionnaires were entered in Excel spreadsheets. In the fourth workshop, the data were transferred into SPSS for validation, analysis, psychometric testing and design of the latest version of QUOTE-TB.

The most important dimensions of quality of care for TB patients in Malawi, Kenya and Uganda are:

- Availability and accessibility of TB services;
- Information to TB patients;
- Provider interaction and counselling;
- Infrastructure;
- Procedures and tests;
- Costs and payments;
- TB/HIV relationship; and
- Support.

Implementation:

This QUOTE-TB tool is ready for implementation in Malawi, Kenya and Uganda, and in other East African countries with similar cultural settings. QUOTE-TB should be introduced to other countries and implemented after country-specific adjustment.

Introduction and rationale

The increasing TB problem worldwide: main strategies and services

Tuberculosis (TB) is a chronic infectious disease, affecting about 9 million individuals per year and leading to approximately 2 million deaths. Although most TB patients can be cured with good treatment within six to eight months after diagnosis, TB can affect a person for a much longer period. There are often delays before the diagnosis is made, causing prolonged suffering.

A number of patients fail to respond to treatment or get TB again after finishing treatment. Increasingly, there are patients with multi-drug resistant TB (MDR-TB), requiring treatment for more than two years. Co-infection with HIV leads to complicated management of TB, with the need for many different drugs over longer times. It is assumed that good-quality TB services, especially from the patient's perspective, will lead to earlier diagnosis and better treatment outcomes, by attracting non- and late users of health services. Early diagnosis and appropriate treatment are among the cornerstones of the directly observed treatment short course (DOTS) strategy. The targets to control the worldwide TB epidemic, as recognized by the WHO/Stop TB Partnership and included in the Millennium Development Goals (MDGs), are to diagnose at least 70% of infectious TB cases and successfully treat at least 85% of those.

Rationale to develop a tool to measure the patient's perspective

Under the DOTS strategy [WHO 2002], quality improvement of TB services was specifically focusing on TB laboratory services such as External Quality Assurance (EQA), which is a set of well-defined measures for technical assessment and improvement of those laboratories involved in direct sputum smear examinations. In addition, quality improvement of National TB Programmes (NTPs) under DOTS is based on the classical quality elements of structure, process, and outcome. Quality improvement procedures include supervision, training, peer review, and recording and reporting for monitoring and evaluation and laboratory services.

However, patients' perspectives have been missing. For instance, if NTPs use supervision checklists, few are addressing the patient perspective in a standardized way. Patient satisfaction and the wider concept of responsiveness and quality as seen through the eyes of the patient are decisive factors for delays in diagnosis and compromised adherence to

treatment, resulting in prolonged transmission of infection in the community, development of drug resistance and increased TB mortality.

Therefore, effective and simple tools are needed to assess the technical and interpersonal aspects of the quality of services at the interface between health staff and patient. One such tool would be a standardized tool for patient interviews, which capture patient perspectives and which are easy to analyse and interpret by NTP staff during routine supportive supervision. Also, while comprehensive NTP reviews do address patient satisfaction through questionnaires, these tend to differ from one review to another and are not standardized and validated. In addition, their analysis is usually cumbersome, difficult to quantify and, therefore, hard to use as an analytical management tool.

Patient perspective and the new Stop TB Strategy

The new WHO Stop TB Strategy combines the five pillars of the DOTS strategy with elements of the DOTS expansion strategy [WHO 2006]. The five pillars of DOTS are:

- political commitment;
- a quality-assured laboratory network for bacteriological diagnosis of TB;
- standardized treatment with short course regimen;
- uninterrupted drug supply; and
- accountability through a recording and reporting system, supervision, monitoring and evaluation.

The new strategy is formulated in such a way that its underlying principles have quality improvement as a cornerstone.

The four major additional objectives of this strategy are:

- To expand access to high-quality diagnosis and treatment for people with TB;
- To reduce the human suffering and socio-economic burden associated with TB;
- To protect vulnerable populations from TB, TB/HIV and drug-resistant TB;
- To support the development of new tools and enable their timely and effective use.

Specifically featuring in the new strategy is the empowerment of patients and communities. One of the established approaches is Community TB Care, whereby more responsibility lies with patients and communities to better

respond to individual patient's needs, without compromising the DOTS principles. Also new is the focus on patients' rights and responsibilities, as outlined by a group of ex-TB patients from around the world in the Patients' Charter for Tuberculosis Care [World Care Council 2006]. The aim of this document is to empower people with TB and their communities and enhance the relationships with health care providers. It addresses the following patients' rights:

- Care: equitable access, without discrimination, to TB education, prevention and care according to established standards of care, including the needs of TB patients with MDR-TB and HIV co-infection;
- Dignity: TB services in a respectful environment, without stigma, and with moral support from the community;
- Information: on all aspects of TB, including prognosis, costs, side effects and other consequences, and to share experiences with peers;
- Choice: to have a second opinion, access to medical records, accept or refuse medical interventions and to take part in research;
- Confidence: personal dignity, privacy and confidentiality about medical condition;
- Justice: the right to complain, to appeal and to be heard promptly and fairly;
- Organization: participate as stakeholders in policies and programmes and establish TB patient platforms;
- Security: job security and rehabilitation, nutrition security or food supplements if needed.

TB patients also have responsibilities to share information and to take their medicine, to contribute to community health and to show solidarity. These are also outlined in the above-mentioned document.

Many TB patients prefer private health services. Private practitioners diagnose and treat a substantial number of TB patients, often without following the NTP guidelines for standardized diagnosis and treatment. To improve diagnosis rates, to ensure a high quality of care and improve collaboration in some public health functions, the new Stop TB Strategy also emphasizes Public/Private Partnership (PPP) initiatives. For this purpose, a very useful document has been produced: the International Standards of TB Care [TBCTA 2006]. However, the involvement of TB patients in Advocacy, Communication and Social Mobilization (ACSM) activities to get TB-free communities, and the involvement of patients in the decision-making processes of NTPs, are important aspects that hitherto have been insufficiently addressed.

Finally, a 'pro-poor' agenda is needed, whereby a government commits to poverty reduction by making DOTS available to all, including poor people, through decentralization of DOTS, other geographical targeting of poor people, removal of financial barriers and by encouraging health staff to provide high-quality care to poor people. A 'pro-poor' agenda may include food incentives for poor patients, deposit schemes with (partial) reimbursement to enhance adherence, a reduction in the number of visits to clinics, community-based DOTS projects, monetary incentives for (community-based) providers, and initiatives for PPPs. All these are incentives aimed at improving the quality of care to individual patients [WHO 2005].

To support these initiatives, there is a strong need for an instrument to measure quality of TB care from the patient's perspective. A vast body of literature exists about patient and client satisfaction, and quality of care. We refer here to Annex A: Why this tool? A search through literature.

Background to QUOTE

Development of QUOTE (Quality of Care as seen through the Eyes of the Patient) in The Netherlands originated from patient satisfaction studies based on the value expectation model [Linder-Pelz 1982], followed by models based on perceptions and expectations [Parasuraman 1985/1988]. The Performance-Importance-Impact model [Zastowny 1995] built on this work and was developed by NIVEL to empower patient organizations and to promote the patient's perspective [Sixma 1998].

QUOTE has been used for quality assessment and improvement for patients in several chronic disease categories in mostly European countries, such as Chronic Obstructive Pulmonary Disease [Van Campen 1997], rheumatic disease) [Van Campen 1998], frail elderly people [Sixma 2000], disabled people [Sixma 2001], HIV/AIDS [Hekkink 2003], Irritable Bowel Disease [Van der Eijk 2001], cataracts [Nijkamp 2001 and 2002] and Diabetes Mellitus.

The motivation for departure from the traditional tools of measuring the quality of services to the utilization of QUOTE is based on several advantages of QUOTE over other methodologies [NIVEL 2005]. QUOTE is patient centred, in that it recognizes that different groups of patients have specific needs which are unique for their disease. Ultimately, the specific needs, experiences and expectations of patients can be evaluated using QUOTE. In addition, the tool considers patients' perceptions, since their views are critical in its development. This is the main contrast with other tools, since these are often developed based on researchers' viewpoints, thereby posing a risk of compromising the patient's views. The questions asked in QUOTE focus on expectations and experiences rather than on

patient satisfaction and thus often elicit high satisfaction rates from the majority of patients [NIVEL 2005].

In the USA similar developments have led to the Consumer Assessment of Health Plan Surveys (CAHPS) approach, while in the UK instruments developed by the Picker Europe Institute are based on the same principles.

In Kenya, Malawi and Uganda a TB patient exit interview tool has been developed as part of the Performance Improvement Approach (PIA). All these new 'state of the art' quality of care measuring instruments focus on reports instead of patient satisfaction and/or ratings.

A synthesis of the three developments (CAHPS, QUOTE and PIA exit interviews) has resulted in QUOTE-TB. It borrows the importance component, flexibility of use and the idea of having disease-specific quality of care questions from the QUOTE approach. The basic framework of answering categories and evaluating questions is derived from the CAHPS methodology, whereas the mode of administration, TB-specific questions and open questions are taken from the TB patient exit interview of the PIA.

This development of QUOTE-TB built upon the initiative taken by the Regional Centre for Quality Health Care (RCQHC) in Kampala, Uganda, to introduce the PIA for TB control. The RCQHC aims to assist NTPs to improve performance of staff at district and peripheral level. Checklists for observation and client exit interviews are developed and introduced to supervisors through training. These tools are to be integrated in regular supervision activities.

QUOTE-TB, an adaptation of or variation on the generic QUOTE tool, was developed in two phases: namely, first a qualitative study to determine the dimensions of the quality of TB care as perceived by patients; followed by a quantitative study phase in which the instruments developed after the first phase were validated.

QUOTE-TB consists of two questionnaires: one aims at measuring the performance of the services delivered in TB facilities from the perspective of patients; the other rates the importance of quality dimensions of TB services. The combination of the two gives a quality impact score of the performance as seen through the eyes of the patient.

VOLUME 1: HOW TO USE QUOTE-TB

1. Guide to using QUOTE-TB

QUOTE-TB is a management tool which allows NTPs to measure the performance of TB services from the patient's perspective at the health facility and to focus quality improvement interventions at the various levels of health care. It could be used by NTP supervisory staff as part of supervision activities, with the assistance of health staff trained to take interviews.

As explained in the previous chapter, QUOTE-TB consists of the following parts:

- A questionnaire to assess the **performance** of TB services as experienced by patients, to be routinely used at various levels with data being collected regularly (for instance, once every four or six months). The performance questionnaire is included in Annex C. The average time taken for a performance interview in Kenya, Uganda and Malawi was approximately 10 to 20 minutes per patient.
- A questionnaire to identify which quality issues are **important** to patients; these issues being determined at country level and limited to once every five years, or whenever major changes to the health services have taken place. This importance questionnaire is included in Annex B. The average time taken for an importance interview, including ranking, in Kenya, Uganda and Malawi was approximately 35 minutes.
- The essence of QUOTE-TB is to calculate the **quality impact** (QI) score, by multiplying the importance and the performance scores.

Routinely, the performance questionnaire can be used to interview registered TB patients who come for consultation in a particular health facility or hospital. Health facilities could include private clinics linked to the NTP under the PPP of the new Stop TB Strategy. Another interesting group of TB patients includes defaulters, as they have been in contact with health services and, therefore, are able to judge their performance. Serious attempts should be made to interview them as well. TB patients treated under the community TB care approach have, by definition, limited experience of the performance of the health facility, apart from the diagnostic process and being offered the option of community treatment.

The information from the interviews can be used as a performance measuring tool, for instance as part of the patient exit interview under the PIA. To get reliable results for the impact score of a health facility – by combining the performance scores with the importance scores – at least 50 patients have to be interviewed in that facility, either in one or in more sessions. This will be discussed further in this chapter.

In addition to the questionnaires, so-called 'picture cards' have been developed which visualize dimensions of quality of care and can be used to discuss quality of care with patients. These picture cards were used for ranking procedures of the quality dimensions during the field testing of QUOTE-TB in Kenya, Uganda and Malawi. They are shown in Annex F: Picture cards for ranking and instructions for using.

District NTP staff should appoint interviewers who are then instructed and asked to interview TB patients in a certain health facility. It is important that the interviewer is NOT related to the health facility in any way, to avoid TB patients giving inaccurate answers. Examples of different possibilities are: staff from an NGO, staff from the Ministry of Social Affairs, health providers from a neighbouring facility, etc.. A set of instructions to interviewers as developed and used by the research team is included in Annex E: Training instructions.

If investigating the perspective of defaulters on TB service performance is seen as a priority, QUOTE-TB should be used to interview defaulters. This might provide useful new insights, which would not be revealed otherwise. However, this requires extra effort, funds and ethical considerations.

The NTP manager should plan quality of care activities, such as using QUOTE-TB, discuss and arrange remuneration of interviewers, and include this in the NTP budget for either monitoring and evaluation or quality assurance.

This chapter describes in detail the use of QUOTE-TB at the different levels: national, district, and health facility. It describes for each level the aim of the tool, how data can be analysed and how information can be used to improve quality of care, as follows:

- **National level:**
 - External national review of NTP to measure patient perspective
 - Internal ongoing monitoring of NTP performance and benchmarking: nationwide view, e.g. identifying differences between districts, and between facilities within districts
 - Analysis of all reviewed health facilities and benchmarking at the district level: overall view of quality of care by district and of differences between health facilities
- **District level:**
 - Analysis of all reviewed health facilities and benchmarking at the district level: overall view of quality of care by district and of differences between health facilities
- **Health facility level**
 - Use QUOTE-TB in facilities with more than 50 registered TB patients

- Facilities with less than 50 TB patients:
 - Use QUOTE-TB for aggregate analysis of health facilities at district level
 - Use the outcome of the performance interviews without linking with importance scores
 - Use picture cards in focus group discussions to improve services at facility level

How to calculate and interpret performance, importance and quality impact scores

The most practical method – and probably the easiest to understand – to analyse the performance and importance data from the questionnaires is presented here. A more detailed description, including other methods, is provided in Volume 2.

Performance and importance ratings need to be combined into so-called quality impact (QI) scores which can be used in projects that aim at selecting and/or improving quality of care target areas or specific points from the TB patient's perspective.

The following 10 quality aspects have been selected to illustrate the use of QUOTE-TB for quality assurance and improvement purposes. The table shows an example of performance and importance scores and the calculated QI scores for these 10 selected quality aspects, whereby:

- **Performance scores:** the percentage of respondents who answered 'sometimes' and 'never' or 'no' in performance questionnaires.
- **Importance scores:** the percentage of respondents in the 'extremely important' category in the importance questionnaires.
- **Quality impact scores:** a combination of performance and importance scores, by simply multiplying the two scores and dividing by 1000.

Table 1: Sample statistics (performance scores, importance scores, quality impact scores).

Quality aspect	Performance (% negative reports)	Importance (% extremely important)	Quality impact (QI)
A. Are the <u>waiting times</u> before being served by health care providers at this TB facility acceptable for you? (never – sometimes – usually – always)	32.4	46.6	1.51
B. How often are <u>drugs available</u> at this facility when you require them? (never – sometimes – usually – always)	16.0	77.9	1.25
C. Do the health care providers at this facility tell you about the <u>side effects of TB drugs</u> ? (no – yes)	29.6	65.1	1.92
D. During your visits to this TB facility, how often do the health care providers treat you with respect? (never – sometimes – usually – always)	10.1	69.0	0.70
E. During your visits to this TB facility, how often do you have sufficient time to discuss your problems? (never – sometimes – usually – always)	33.3	60.9	2.03
F. Did health care providers at this TB facility inform you about the link between TB and HIV? (no – yes)	21.4	70.5	1.51
G. How often are the toilets at this TB facility usable? (never – sometimes – usually – always)	31.5	73.6	2.32
H. Were you physically examined during your first visit to this TB facility? (no – yes)	28.9	71.8	2.08
I. How often do you have to pay a tip at this facility to receive your TB services? (always – usually – sometimes – never)	1.2	81.7	0.10
J. How often do you receive food support from the TB facility? (never – sometimes – usually – always)	94.2	51.9	4.89

Here is a detailed description of how to calculate the scores, based on the example above.

- The **performance scores**: a way of calculating performance scores is by looking at the percentage of respondents that rate an item as negative. For instance, for item A (see table) the performance score indicates that 32.4% of the respondents answered that they are 'never' or only 'sometimes' faced with acceptable waiting times. The remaining 67.6% answered that waiting times before being served are usually or always acceptable. Although some information is lost, because the two positive and the two negative answers are taken together, this way of presenting performance data is easy to use with four- and two-point answering categories and easy to interpret. For the 10 quality aspects in table 1, performance scores based on the percentages of negative reports vary between 1.2% (item I) and 94.2% (item J). In this scenario, the higher the score, the worse the performance is rated. The advantage of this calculation is the ease of computing and understanding the results. Another advantage is the possibility of computing the QI score in combination with the importance score (see below).
- The **importance scores**: a way of presenting importance scores is by looking at the percentages of respondents that rate an item as 'extremely important'. For item A the importance score of 46.6 indicates that 46.6% of the 339 respondents rated this particular item as 'extremely important'. For all 10 items in this example, percentages of respondents answering 'extremely important' vary between 46.6% and 81.7% (item E). In this scenario, the higher the score, the more important an item is rated. The advantage of this calculation is the ease of computing and straightforward understanding of the results. It also offers the possibility of computing the QI score in combination with the performance score (see below).
- Finally, the essence of QUOTE is the **quality impact score**. These scores are derived from combining the performance scores and importance scores. As an example we look at the QI score for item A. The QI score of 1.51 for this particular item is the result of multiplying the performance score with the importance score, divided by 1000. Or in figures: $(32.4 \times 46.6)/1000 = 1.51$. For the 10 sample items in table 1 the QI scores vary between 0.10 (item I), which indicates hardly any room for improvement, and 4.89 (item J). The maximum score theoretically possible is 10, indicating that 100% of the patients perceive poor performance of those TB care aspects considered extremely important. The higher the QI score, the more room or necessity for improvement.

Although it is difficult to give exact criteria, in general one might say that QI scores above 1.00 indicate that improvement is possible and maybe necessary.

Using separate parts of the tool, performance and/or importance scores can be calculated to measure individual items or broader dimensions of TB care. If sufficient data are available, these scores can be broken down by different subgroups of respondents (e.g. by gender, educational level, age category) or by TB facility and country characteristics (e.g. urban/rural, hospital/health centre/dispensary, government/private).

In annex D: Details of importance scores and ranking, the overall importance scores are given for the present version of QUOTE-TB, as well as a breakdown of these importance scores according to gender (male/female), residence (urban/rural) and educational level (high/low).

Use of QUOTE-TB at national level

Option 1: national programme reviews

Aim: to measure at national level the QI scores of the quality of care from TB services from the patient's perspective and to provide feedback to the programme management on the quality of TB services as perceived by patients in different regions of the country and for different groups of patients.

What: at national level QUOTE-TB can be used as part of the annual review of NTPs, to measure quality of care in a standardized way.

How: formulate clear questions for data analysis, such as comparing results between men and women, between regions or between urban and rural areas, between public and private settings. Use the available information from the questionnaires and calculate QI scores for each item at national level. Expertise in organizing and conducting meetings is required, as well as in leading discussions.

Use of results: include the patient's perspective in the overall report and discuss options and strategies for improvement. If the QI scores are very high, you may also think about contracting out a study to a research group.

Option 2: internal review and ongoing monitoring of quality improvement and benchmarking

Aim: to discuss and learn by comparing interventions aimed at improving aspects of service provision from a patient's perspective and methods to involve TB patients in these interventions. It also aims to provide a nationwide view of quality of care and analyse differences between districts, and between facilities within districts.

What: QUOTE-TB can be used for internal ongoing monitoring of NTP performance and benchmarking, focusing on differences between districts.

How: calculate and compare the QI score for each region or province, using the available information on performance. Collect information on quality improvement interventions initiated in the different provinces or regions, by asking each management team to summarize on two pages what was done, by whom and how, and including successes and difficulties encountered. Relate the quality improvement interventions to the QI score and identify which regions or provinces have actually used the information from QUOTE-TB to initiate changes.

Use of results: provide feedback to provincial supervisors and to the national TB team and their stakeholders during a national planning or debriefing meeting. Special attention has to be paid to make sure that TB patients or their representatives are included in this meeting. Discuss in the

meeting quality of care interventions: methods for priority setting, examples of good practices, involvement of TB patients in all stages of interventions, etc.

Options 1 and 2: stakeholders to be directly involved in the interviews include representatives of TB patients, provincial and district TB control managers, the national NTP team and other Ministry of Health officials, and representatives of private health care providers. Others to include in discussions are policymakers and planners, AIDS programme managers, other health care providers, community representatives, consumer groups, TB patients and patient organizations, and managers and providers of social services. It should also be part of the agenda during meetings of national TB associations and other NTP steering committees.

Expertise required: at the national level, data analysis needs to be conducted by a social scientist with skills in SPSS (refer to Volume 2, Chapter 2.4). Detailed analysis can be done by age, gender, urban/rural setting, educational level, type of facility, etc. (see example in Annex D: Details of importance scores and ranking). Feedback meetings at national level should be facilitated by the NTP manager or a staff member responsible for quality of care. The facilitator should understand QUOTE-TB and the results of the data analysis: good presentation skills and skills in leading discussions are required.

Financial resources required:

- Remuneration of a social scientist, if not employed within the Ministry of Health
- Remuneration of costs of meeting: location, refreshments, copying of paper
- Costs of stakeholders' meetings

All these activities need to be planned and budgeted for by the NTP manager.

Use of QUOTE-TB at district level

Aim: to measure at district level the QI score of the quality of care from TB services from the patient's perspective and to provide feedback to health services on the quality of TB services as perceived by patients.

What: at district level QUOTE-TB can be used to measure the QI score with respect to the quality of TB services and to provide feedback to health facilities on the overall situation with respect to the quality of TB services at district level. This feedback can be used at facility level to discuss changes. Expertise in organizing and conducting meetings is required, as well as in leading discussions.

How: combine the interviews conducted in health facilities in the district to allow a robust analysis, including the facilities in which fewer than 50 TB patients were interviewed. Compare results of the QI scores between different facilities, although careful interpretation is needed when dealing with small numbers.

Use of results: provide feedback to health care providers and managers of facilities during a regular district meeting and invite a number of TB patients to share and discuss the results. Develop quality improvement interventions at local level. At district level, during a regular meeting the QUOTE-TB results can be explained and discussed⁷. During this meeting the QI scores for the most important issues (both positive and negative) need to be presented and analysed.

The QI scores can be used in priority setting, to select interventions for improvement. Priority setting can be done either in order of QI score or by deciding the minimum acceptable level of this score and discussing all or a certain number of the issues scoring higher than the acceptable level.

It is also important to discuss who is responsible for action, since some issues needing improvement might not be solved at the facility level and need to be addressed at district level. For instance, if the QI score on 'giving information on the relationship between HIV/AIDS' is high and it appears that TB service providers do not have the skills to do this, the district TB supervisor might need to organize training or provide the facilities with educational materials.

Subsequently, each facility is requested to discuss during its own staff meetings the issues that can be addressed at facility level, and to involve patients in these discussions. An example is provided in box 1, below.

⁷ It is important for the facilitator to have a 'problem-solving' attitude and that participants do not blame each other when certain issues have a high QI score

Box 1. Example of discussions about quality improvement

In a district the TB supervisor has organized a meeting with all TB service providers in the district to give feedback on the quality of care from the patient's perspective. The data analysis showed that the highest QI scores for all facilities were 'friendly attitude' (7.4), 'food support' (6.5) and 'information on HIV/AIDS' (6.4). The TB supervisor explained that this meant that in these three areas quality needed to be improved because:

- friendly attitude, food support and information on HIV/AIDS were considered important by TB patients;
- in many facilities TB patients had experienced unfriendly health care providers, many were not offered any food, and many did not receive HIV/AIDS care.

The health care providers present at the meeting discussed with each other and with the patients who were present what they could do about these issues. All agreed that food support needed to be discussed with the HIV/AIDS programme management and with the local government at district level, and the TB District Supervisor agreed to take up this issue. The participants of the meeting agreed that the other two issues could be solved in the facilities. They decided to discuss these two issues in their own facility with some of their TB patients.

Quality improvement interventions at the district level need follow-up. The patient's perspective on quality of care and the use of QUOTE-TB results should become part of regular meetings that address quality at district level and feature in the progress reports for the national level. Information from QUOTE-TB can also be included in the routine supervision reports in the district.

Stakeholders to be directly involved in activities include TB patients, TB service providers and their managers at facility level, representatives of private providers and district TB control managers.

Other stakeholders to be considered for inclusion in discussions are other district health team members, members of the community, AIDS programme managers, private health care providers, managers and providers of social services, and local government.

Expertise required: the basic calculations can easily be done by hand, or by using a simple Excel spreadsheet. An example of a usable Excel spreadsheet for data entry is included on the CD-ROM in this guide. The only expertise required is the capacity to calculate percentages. More sophisticated analysis could be performed as well but requires a social scientist with skills in using SPSS (refer to Volume 2). Feedback should be organized during the routine NTP management meetings at district level and facilitated by the district TB supervisor.

Use of QUOTE-TB at health facility level

Aim: to identify at health facility level patients' experiences of the performance of TB services and to select aspects that require improvement from the patient's perspective.

Option 1: use QUOTE-TB for quality assurance and improvement

What: at facility level, QUOTE-TB can be used as an instrument for quality assurance and improvement, for instance in combination with the Performance Improvement Approach (PIA). Most quality and performance improvement cycles start with problem identification. To better include a patient perspective, the stage of problem analysis can be preceded by exit interviews using QUOTE-TB to measure performance. The results of these exit interviews allow the identification of those aspects of service delivery with which a relatively large number of interviewed TB patients had negative experiences and which they regard as very important.

The way in which QUOTE-TB is used depends on the number of TB patients in a facility.

How: in health facilities that have more than 50 TB patients, the QI scores can be used for all the items. Discuss the results and set priorities for action. The priority setting can be done either in order of importance or by deciding the minimum acceptable level of QI score and discussing all or a certain number of the issues scoring higher than the acceptable level. An example is provided in box 2, below.

Box 2. Example of calculating and interpreting the quality impact score

At a health facility you and your fellow health care providers agreed that the quality of service delivery would be rated as too low (unacceptable) if 15% or more of the patients answered negatively on certain performance questions. Subsequently, you interviewed 50 patients between January and March 2006. When the interviews were analysed you discovered that 15 patients answered that they **never** had sufficient time to discuss their problems, and five answered that they **sometimes** had sufficient time to discuss their problems.

This means that, in total, 20 patients out of 50, or **40%**, did not feel that they had sufficient time to discuss their problems. In other words, more than the acceptable 'threshold' of 15% were not satisfied with the performance. The importance score for 'having sufficient time to discuss your problems' was established to be **61%** (see earlier in this chapter). The QI score is, therefore, $40 \times 61 / 1000 = \mathbf{2.44}$.

Generally, QI scores higher than 1 can be considered as unfavourable and need to be addressed.

When setting priorities for quality improvement interventions, you will compare this QI score with those of other items before deciding which issues to tackle first.

Health facilities with fewer than 50 TB patients: although the number of interviewed patients will be too small to reliably calculate the QI score, the answers of the patients with similar experiences in performance will still give an impression about the experiences patients have with the quality of the services, and as such the results can be used to discuss areas for improvement at local level. An example is provided in box 3, below.

Box 3. Example of discussions based on performance scores

A health centre covers a population of 15,000 people and currently has 30 TB patients on DOTS. In this facility, over the period January to March 2006, the interviewers managed to conduct exit interviews with 20 patients.

Given the low number of patients, the centre decided to use the results to identify which aspects of care had a minimum number of 10 people with negative experiences.

The results of the interviews showed that 11 of the interviewed patients sometimes or never had the opportunity to discuss their problems.

This information was used to discuss how to improve upon this aspect of performance.

Using the results: for both large and small health centres, the interview results can be used to set priorities for improvement, by organizing a meeting (or several meetings) with representation from TB patients and health service providers and their managers, to discuss feedback on the interviews, to set priorities for action and to formulate interventions for improvement.

A plan of action will need to set priorities for interventions. This can be done using criteria such as the minimum acceptable level of people who have negative experiences with services. When more than 50 patients are interviewed and the QI score is calculated, the items with the highest QI score can be selected.

If several interventions have been proposed, but not all can be implemented, additional selection criteria can be used for further prioritization. In one of these methods, additional important selection criteria are defined, such as feasibility of the interventions, given the operational context. Each of these selection criteria is then assigned a certain amount of points to be distributed among the different issues, by voting or other means of reaching consensus.

An example of a prioritization matrix to use in decision making is presented in table 2, below.

Table 2: Example of a prioritization matrix (fictive), where one of the weighing factors is the patient's perspective (QI score).

Issue	QI score (patient perspective)	Feasibility (cost effective, easy to do)	Total (sum of previous two columns)
Food support			
Friendly attitude			
Opening hours			
Total scores			

Further analysis and discussion of the negative experiences are discussed in the regular management meetings. Identify why these negative experiences occur and identify opportunities for improvement. The management team of the health facility needs to develop a plan of action for improvements.

The action plan needs to include the following components:

- intervention topic
- reason why this intervention is believed to be successful
- objective of the intervention
- activities
- team members
- time frame for implementation
- financial, material and human resources required
- indicators for monitoring and evaluating change

Let the team introduce the plan of action during a staff meeting, discuss feasibility of implementation, and discuss and agree upon changes. These meetings need to be initiated by the facility manager and the TB service provider. Start implementation of the plan.

After an average of four months of intervention, a number of patients can be interviewed again to assess if the interventions have achieved the desired results, and experiences with these aspects have become more positive.

It might be possible for NTP managers to reward initiatives developed by service providers and TB patients that result in improved quality as perceived by patients, to keep motivation for quality improvement high. Rewards can be financial or non-financial.

Stakeholders to be directly involved in activities include TB patients, and TB service providers and their managers at facility level. Other stakeholders to be considered for inclusion in discussions at local level are local government and Ministry of Health representatives, service providers, members of the community, TB patients, managers, private health care providers, and providers of social services.

Expertise required: the interviews can be relatively easily analysed at facility level, by hand or using an Excel spreadsheet. Skills in calculating percentages are required. An example of a usable Excel spreadsheet for data entry is included on the CD-ROM in this guide.

Meetings on priority setting and discussions on interventions should be organized by the facility manager or the TB service provider. Facilitation and presentation skills are required. Expertise in organizing and conducting meetings is required, as well as in leading discussions.

Resources required: cost estimates related to the implementation of action plans and the participation of TB patients in each facility should be proposed by facility managers and integrated into the budget by the district supervisor. Expertise in organizing and conducting meetings is required, as well as in leading discussions.

Option 2: participatory methods to discuss quality improvement at facility level

At facility level a participatory method can be used to discuss quality and quality improvement with TB patients.

What: QUOTE-TB is still used to conduct interviews with TB patients as described in option 1, but the interviews are sent to the district level for aggregate analysis to calculate performance and QI scores and to provide feedback to all the centres in the district on their performance from the patient's perspective (see use at district level).

How: every six months, organize between two and four focus group discussion with TB patients⁸, using the visualization cards (see Annex F: Picture cards for ranking and instructions for using) to ask them about their experiences with different aspects of care and get their ideas for improvement. A guide for discussion facilitation is provided in box 4, below.

⁸ it is best to limit the number of discussion groups, but at the same time assure that different groups of people have the opportunity to voice their opinion. The number of groups required depends on the socio-cultural situation. For instance, in many countries men and women need to discuss issues separately.

Box 4. Guide for discussion with patients

Welcome the patients and explain why they are being asked to attend this discussion and how the results of the discussion will be used.

Introduce yourself and ask the patients to introduce themselves.

Explain that it is important that they speak openly about their experiences and that there will be no negative consequences if they criticize a certain service.

Explain the process of the discussion and that you will work with picture cards.

Show all the cards and ask the participants to describe what they see.

For each card ask the participants the following questions (probe):

- What do you think about this issue at the facility where you go for your TB services?
- What is good? What do others think?
- What could be improved? What do others think?

When you have completed discussing all the cards, ask the following:

- Given what we have discussed, what do you think is the most important issue to improve? What do others think? (Try to reach a consensus on a number of issues.)
- For the issues we have identified as needing improvement, how can this improvement be done, and what role can the community and TB patients play?

Summarize the answers and ask if anyone wants to add anything or wants to ask a question.

Thank all the participants for their contributions and ask two participants to volunteer to participate in the feedback meeting to providers and managers of the facility.

These focus group discussions should, as much as possible, coincide with another event or be organized at village level, to avoid long journeys for patients.

Use of results: organize a feedback meeting with health care providers and managers of the facility and invite a number of participants from the TB patients' discussion group to participate too. During this meeting, TB patients should present the results of their discussions and should be involved in discussions on quality improvement interventions. The options for improvement should be discussed further with representatives of the TB patients, priorities set and work plans developed.

Monitoring the results of quality improvement interventions is accomplished in subsequent discussion groups, where changes in experiences will be discussed and new areas for improvement identified, using the method described above. In addition, the data collected during the exit interviews

and aggregated at district level should show changes in trends as a result of quality improvement activities.

Stakeholders to be directly involved in activities include TB patients, and TB service providers and their managers at facility level. Other stakeholders to be considered for inclusion in discussions at local level are Ministry of Health officials at local level, health care providers, members of the community, TB patients, managers, private health care providers, and providers of social services.

Expertise required: use of participatory methods.

The feedback meeting should be facilitated by the manager of the health facility. Facilitation and presentation skills are required.

Financial resources required: payment for transport and meals for all participants in these meetings should be budgeted for by the TB district supervisor.

Dissemination of QUOTE-TB

This version of QUOTE-TB (see Annex B and C) was developed for Kenya, Uganda and Malawi, based on a combination of qualitative and quantitative research. During this process it was established that the present version covers relevant quality of care aspects from the perspective of TB patients in the three participating countries. Therefore, the validity of the tool was established for these three countries. Before it can be used in other countries, a process of cultural validation is necessary. As part of this process the following steps are mandatory:

- additional qualitative data collection with stakeholders (TB care providers, TB managers, TB experts in the Ministry of Health) through interviews and/or group discussions, to establish the relevance of all quality aspects in this version (Annex B and C) for the national situation, to find out if there are any relevant quality aspects missing and to validate the layout of the tool from the perspective of these respondents. A minimum of two group discussions and/or 10 in-depth interviews is recommended;
- additional qualitative data collection with TB patients and representatives of organizations of TB patients through interviews and/or group discussions, to establish the relevance of all quality aspects in this version (Annex B and C) for the national situation, to find out if there are any relevant quality aspects missing and to validate the layout of the tool from the perspective of these TB patients. Again, a minimum of two group discussions and/or 10 in-depth interviews is recommended.

Major changes in the current version will result in further quantitative testing, according to the framework that is presented in Volume 2 of this guide.

Use of QUOTE-TB in different settings

In countries where socio-economic and cultural settings are totally different from those in Kenya, Malawi and Uganda, QUOTE-TB has to be adapted and validated, and extensive fieldwork has to be carried out from the start.

The procedures to do so are described in Volume 2 of this guide: 'Guide to developing or adapting QUOTE-TB'.

Follow-up research

With the implementation of the new version of QUOTE-TB in Malawi, Kenya and Uganda, more empirical data will become available.

With these additional data it will be possible to explore its psychometric characteristics in greater detail and further adjust the questionnaire accordingly. In particular, further optimization of correlation and reliable scales can be achieved, providing importance scores specific for the country. Also, the ability of QUOTE-TB to correctly discriminate between districts and at the level of health facilities could be established. This would make QUOTE-TB even more powerful as a benchmarking instrument for detailed quality issues and differences. Finally, to achieve a fair comparison between the different districts and/or facilities, it might be advisable to adjust the quality of care ratings for some of the respondent characteristics (like age and educational level) and for district or facility characteristics.

More details of suggested QUOTE-TB follow-up research activities are presented in Volume 2.

VOLUME 2: GUIDE TO DEVELOPING OR ADAPTING QUOTE-TB

2.1. Development of QUOTE-TB in nine steps

The essence of QUOTE-TB is that it is disease and setting specific. This means that where one or both of these aspects differ from the settings mentioned in this guide, adjustments have to be made.

TB patients' perspectives are likely to be different between countries; for instance, countries with high and with low HIV prevalence and with high and low multi-drug resistant/extensive drug resistant TB (and M(X)DR-TB) problems.

Although cultural settings in this guide are not well defined, it is clear that countries with different cultures from the East African setting, with differences in poverty-related factors, health systems and service infrastructures, with different health insurance systems, etc. all require adjustment of QUOTE-TB.

In this chapter the nine steps of how to develop QUOTE-TB are presented. Examples are provided from Kenya, Malawi and Uganda, where it was originally developed.

An overview of the activities and workshops necessary to develop QUOTE-TB is presented below in Table 3. This table includes a time-line, with sequence and approximate duration of the respective activities.

STEP 1. Orientation

The first step concerns orientation with the national health authorities, research bodies and their partners – creating political commitment and ownership. It is important to involve NTP managers and Ministry of Health representatives from the onset of the QUOTE process; without their consent the whole process fails, so they should be in favour of the process.

- Orientation of stakeholders workshop;
- Establishment of a QUOTE-TB committee: define roles and responsibilities in writing, including its composition, terms of reference, frequency of meetings;
- Adoption of a QUOTE-TB programme in the national TB guidelines for one year;
- Development of a one-year costed operational plan in close collaboration with all partners.

Table 3. Overview of activities to develop QUOTE-TB

Step	Time-line
1. Orientation	
2. Workshop: Identification of quality issues in TB services <ul style="list-style-type: none"> • Familiarization with qualitative research and QUOTE methodology • Obtain skills in qualitative data collection techniques • Obtain skills in data analysis techniques • Develop topic guides for focus group discussions and in-depth interviews • Develop research proposal • Develop action plan and budget for fieldwork • Ask for ethical approval from national ethics committee 	5 days
3. Fieldwork/research through focus group discussions and in-depth interviews to establish quality dimensions and aspects important to TB patients	4 months
4. Workshop: Selection of quality issues in TB services <ul style="list-style-type: none"> • Analyze fieldwork data • Selection of quality issues • Produce research reports • Develop first draft of QUOTE-TB • Develop research proposal for quantification and validation of the tool 	5 days
5. Workshop: Construction of QUOTE-TB <ul style="list-style-type: none"> • Familiarization with ranking and rating procedures of 'importance' items • Field test ranking and rating procedures using picture cards • Evaluate the picture cards • Adjust the QUOTE-TB tools • Prepare research plan for field testing, with adequate sample size and data entry in Excel <p>NB: It is recommendable to combine the workshop under 3 and 4.</p>	5 days
6. Field testing of QUOTE-TB , including training of researchers, data collection, ranking and rating using picture cards	1 month
7. Workshop: Validation, psychometric testing and adaptation of QUOTE-TB <ul style="list-style-type: none"> • Report on research activities • Merge datasets into one database • Familiarize with SPSS • Data cleaning • Reliability testing (scaling) and validation through correlation, factor analysis and data reduction • Adjustment of the final draft of QUOTE-TB • Practical use of QUOTE-TB and interpretation of results 	3 days
8. Final validation of QUOTE-TB <ul style="list-style-type: none"> • Practical use of QUOTE-TB and interpretation of results • Brainstorming with experts and TB patients for final checking on relevance or missed items 	ongoing
9. Implementation, dissemination and follow-up <ul style="list-style-type: none"> • National stakeholder meetings • Involvement of patients at all levels • Feedback from use in the field for further validation 	ongoing

Development of QUOTE-TB can also be looked at as having two phases, namely, a qualitative research phase, in which quality issues are studied and the tool developed in line with the findings, and a quantitative research phase, in which QUOTE-TB also becomes validated.

STEP 2. Qualitative research methodology workshop

A qualitative research workshop should be conducted for one week, during which participants are familiarized with qualitative research methodology, and research proposals are written for qualitative research on the perspectives of TB patients on the quality of care they receive, and what they consider important in the performance of TB services. Participants are also made familiar with the concept of triangulation, whereby other key informants within TB services and control are to be interviewed.

The workshop should consist of interactive introductory sessions on qualitative research issues and group work to develop the proposal. During the workshop the participants should become familiar with in-depth interviews, focus group discussions and observation methods.

Participants should preferably be people from the National TB Control Programme, including a social scientist for each country. The maximum number of participants is five per country and preferably 15 to 20 per workshop.

The objectives of this workshop are:

- Familiarize participants with qualitative research and QUOTE methodology
- Obtain skills in qualitative data collection techniques
- Obtain skills in data analysis techniques
- Develop topic guides for focus group discussions and in-depth interviews
- Develop research proposal
- Develop action plan and budget for fieldwork

STEP 3. Fieldwork to study patient expectations

Each country research team should first ask for ethical approval from the national ethics committee. Informed consent forms have to be developed and used for all interviews. An example is presented in Annex E Training instructions.

After the qualitative research workshop, each country research team should go on to conduct interviews and discussions in the national and/or local languages. The sessions should preferably be audio-taped using a tape recorder. The tapes must be transcribed and translated directly into a word processor by a trained research assistant. Verbatim reports have to be read and compared with hand-written notes of the same sessions.

Each transcript has to be assigned an identification number and then entered into Excel spreadsheets following identified key themes to be investigated. The spreadsheets should be used to summarize the data into common themes for in-depth interviews and focus group discussions, separately. The

process of data analysis involves triangulation of data from the different sources.

Guidelines for research training, instructions and informed consent are included in Annex E: Training instructions.

STEP 4. Workshop to select quality issues for TB patients

A thematic analysis – in which data is categorized along identified themes and patterns in a matrix format – is adopted in a second workshop. Data from these interviews and ranking exercises are entered in Excel sheets. See also Chapter 2: How to analyse qualitative data.

Once the data are organized into themes and patterns, it is possible to interpret the meanings. Salient quotes from the transcripts have to be identified and used in the analysis. The data is analysed in a participatory workshop involving all members of the study teams. The results are used as a baseline to evaluate performance and to develop a quantitative instrument in a participatory way to regularly measure patient's views on the performance of TB services.

Examples from the studies in Kenya, Malawi and Uganda, showing the quality dimensions as perceived by TB patients in these countries, and of other stakeholders (Kenya) and also the ranking of these dimensions (Malawi) are shown below in boxes 5, 6 and 7.

Box 5. Recommendations of patients quoted from the Ugandan study

[Mugisha JF et al. 2005]

Nutritional (food) support: Patients regarded nutritional (food) support highly, so it is suggested that food support should be considered as an integral dimension of high-quality TB services.

Medical examination: Differences in the time taken to produce sputum examination results by the various clinics should be explored and remedied.

Review the scheduling of TB clinic activities: TB clinic managers need to review the opening hours of their clinics. Providers need to be reminded of the need to provide services even in the afternoon. Time-motion studies need to be carried out to determine specific service areas where delays occur in the TB clinics.

CB-DOTS in urban areas: Possibilities of implementing CB-DOTS even in urban settings should be explored on a case-by-case basis with priority given to patients' consent.

Counselling patients: Service providers should ensure that TB patients receive adequate counselling.

Action research: Programme managers should resolve providers' negative attitudes towards TB patients through action research by encouraging discussions among providers. These should focus on reasons for poor provider-client relationships.

Treatment volunteers: Treatment volunteers need to be trained in good interpersonal relations with patients, counselling on side effects and adherence to treatment, and how to overcome potential psychosocial barriers.

Box 6. Recommendations from the Kenyan study [Onyango-Ouma W. 2005]**Patients** list of unhappy experiences**Provider/stakeholder** list of patient unhappiness

Delay/inefficient services
 Negative provider attitudes
 Provider lateness/unavailability
 Long treatment duration
 Strict drug collection times
 Suspicion that one has HIV
 Many injections
 Lack of privacy
 Congestion
 Discrimination
 Open waiting area
 Bad food
 Being asked for a transfer letter
 Weekly drug doses
 Shortage of providers

Shortage of staff
 Delay
 Seminars that take providers away for a long time
 Open waiting space
 Lack of privacy
 Isolation
 Feeling unvalued/stigma
 Lack of full-time services at chest clinic
 Duration of treatment
 Proximity of TB clinic to voluntary counselling and testing (VCT)

Box 7. Scores on aspects of a good TB service in Malawi from focus group discussions (FGD) and in-depth interviews (IDI) [Kapulula P. 2005]	FGD	IDI
Provision of food to patients	53	79
Availability of effective TB drugs	16	42
Less waiting time	10	26
Good health worker attitude	22	19
Provision of education on TB (IEC)	10	18
Good hygiene in the wards	14	17
Provision of drugs to treat other ailments besides TB	11	10
Provision of ARVs to HIV-positive TB patients	3	8
Short TB treatment	2	8
Counselling on HIV/AIDS	3	5
Presence of necessary medical equipment	*	5
Financial support to patients	*	5
Follow-up of patients on treatment	13	5
Microscopy centres near to communities	*	5
Privacy and confidentiality	*	4
Home DOTS	*	4
Drugs provided by the bed in the ward	*	3
Quick laboratory results	9	2
Transportation for patients	*	2
Referral of patients within hospital departments	*	1
Provision of transport to patients on discharge	14	*
No discrimination of patients by health workers	5	*
Short distance to the health facility	5	*
Protection of the wards from diseases	3	*
Feedback of discussions between patients and health workers	5	*
Contact tracing among households of index cases	6	*

*empty cells: issues did not arise

STEP 5. Workshop to construct QUOTE-TB

The new QUOTE-TB tool is drafted during this workshop. The research findings on 'quality of TB care' aspects should be used and combined into a first draft of QUOTE-TB, based on discussions with key NTP staff and the research teams.

QUOTE-TB consists of two questionnaires, one to measure performance of the services and one to establish quality issues that are of importance to TB patients. Each of the instruments consists of four sections, preceded by a page of instructions for the interviewer to greet the patient and to ask for informed consent.

Sections A of the performance and the importance questionnaires are identical (see Annexes B and C respectively). Section A includes questions

on socio-demographic characteristics (gender, age, level of education, main source of livelihood), details on the TB history of the patient (start of the symptoms, time between the onset of the symptoms and first visit to a health provider, when the patient was diagnosed, time between diagnosis and the start of the TB treatment) and specific reasons for visiting the TB facility at the time of the interview.

In Section B of the performance questionnaire, the selected quality aspects are grouped together in broad categories (or 'quality of TB care dimensions'). These quality aspects allow the TB patient to report on the quality of care he/she received at the facility over the period prior to the interview. Respondents are asked to rate specific aspects of the services they received. This can be done either on a four-point Likert scale (categories: 1 'never', 2 'sometimes', 3 'usually', 4 'always') or on a two-point scale (1 'yes', 2 'no').

In Section B of the importance questionnaire the same quality aspects have to be rated on a scale between 1 ('not important') and 3 ('extremely important'). The way the aspects are grouped together should be identical to the format of the performance questionnaire. This rating procedure is followed by a ranking procedure, in which the respondents are asked to rank the different aspects ('quality of TB care dimensions') according to their importance. This ranking procedure should be supported by the picture cards with drawings representing the quality of TB care dimensions (see Annex H: Results of the ranking procedure of quality dimensions for an example from Kenya, Malawi and Uganda).

In both questionnaires Section C concludes with three questions that refer to the overall functioning of the TB facility. The first question is whether or not the respondent would recommend this facility to their relatives and friends (answering categories: 1 'definitely no', 2 'probably no', 3 'probably yes', 4 'definitely yes'). The remaining two questions are 'open questions', asking which services of the facility need improvement and if there are any issues around good quality of TB care that the respondent would like to mention and that were not addressed in the interview so far. This last question can be seen as an indicator of the validity of the tool under development. If new items are disclosed in these questions, they should be considered for incorporation in future versions of QUOTE-TB.

In Section D the interviewer is asked to give some details on the interview setting and the interview itself (see Annexes B and C).

Picture cards are vital in assisting with ranking procedures. The pictures used in the Malawi, Kenya and Uganda were designed by an artist from Tanzania and were field tested during a workshop. Examples of the cards used are presented in Annex F: Picture cards for ranking and instructions for using.

The picture cards included in this guide serve as an example. It is important to develop picture cards locally and field test them to ensure that TB patients understand them and facilitate the understanding of patients of the concepts used in the study.

STEP 6. Field testing of QUOTE-TB

The research team, under guidance of the social scientist, should train research assistants to interview TB patients and to use picture cards for ranking. Guidelines for training and instructions are included in Annex E.

Data are collected through face-to-face interviews, either in English or in the language TB patients would understand best. Interview data (including details on patient characteristics and setting characteristics) are recorded on paper questionnaires, on the basis of one questionnaire per interview/patient.

Sample size can be set at 150 patients for both the performance and the importance questionnaires. The minimum acceptable sample size for quantitative testing is a total of 100 interviews. TB patients who participate in the 'importance' part of the study should ideally be different from the patients who participate in the 'performance' part.

Also in this phase it is crucial to obtain informed consent of those participating in the study. See Annex E for an example of an informed consent letter used in the Uganda study.

During the sampling process the number of respondents that refuse to cooperate and reasons for their refusal should be recorded.

Data from these interviews and ranking exercises are then entered in Excel spreadsheets. See also Chapter 2: How to analyse qualitative data.

STEP 7. Validation and adaptation workshop

In this workshop, the data are cleaned, properly defined and analysed, after transforming them into SPSS system files and combining the performance files and the importance files into one data set. Both data sets are then analysed using the SPSS software package.

Participants are familiarized with SPSS software and shown how to use the specific modules in SPSS for correlation analysis, factor analysis and data reduction (scaling). Experience with this kind of analysis using this software is not always available, so it is recommended that one should ask for technical assistance from institutions with this experience, such as NIVEL, KIT, KNCV Tuberculosis Foundation or RCQHC.

The analysis comprises of explorative data analyses and psychometric testing aiming at the validation and optimization of QUOTE-TB. Data

analyses are performed on the performance and importance data, concentrating on the quality aspects that were included in both test versions of the tool.

Analyses are further explained in Chapter 2.3. They include:

- Item analyses (response percentages, skewness, importance scores);
- Inter-item analyses (correlations);
- Content analyses of items (relevance, description);
- Factor and reliability analyses of dimensions.

STEP 8. Final validation of QUOTE-TB

With the implementation of QUOTE-TB in Malawi, Kenya and Uganda, more empirical data will become available. With these additional data it will be possible to explore its psychometric characteristics in greater detail. Also it will be possible to look at its discriminative power and its usefulness in quality improvement projects. Follow-up research can concentrate on four main topics:

- The structure (taxonomy) of QUOTE-TB;
- Establishing importance scores for the quality aspects of TB care on a national level;
- The discriminative power of QUOTE-TB;
- The selection of case mix adjusters when used in large-scale benchmarking studies.

We refer for further details to Chapter 2.5: Follow-up research for final validation of QUOTE-TB.

STEP 9: Dissemination, implementation and follow-up

Pre-implementation phase

In all countries the tools will be implemented by a trained pool of QUOTE-TB researchers, which needs to be created, preferably by a trainer of trainers.

- Trainer of trainers creates a pool of professionals in each country (nurses, providers, researchers) that can implement the tools;
- Orientation of Health Information Systems (HIS);
- Putting in place SPSS and Excel;
- Team selected to implement tools including HIS staff;
- HIS capable of analysing data and sending them to supervisors and committees.

Implementation phase

For the implementation of the Quote TB please refer to Volume I page 25-44. In this the following possibilities of using Quote TB are described:

- Use of Quote-TB at national level
- Use of Quote-TB at district level
- Use of Quote-TB at health facility level.

In chapter 2.5 (from page 75 onwards) follow-up research for the final validation of Quote-TB is described, which is necessary for implementation of Quote-TB in Kenya, Malawi and Uganda.

Priority setting and follow-up

How to use the results and set priorities after the data have been collected and the scores have been calculated, please refer to Volume I page 25-44:

- Use of results of Quote-TB at national level
- Use of results of Quote-TB at district level
- Use of results of Quote-TB at health facility level

2.2. How to analyse qualitative data for QUOTE-TB

Analysis of qualitative data consists of describing, summarizing and interpreting the data.

Data analysis instructions:

1. Read the research objectives

2. Transcribe the interviews and focus group discussions

The recorded interviews are transcribed into Word documents.

3. Coding and processing qualitative data

- Make piles of your transcribed interviews according to the three districts under study (for instance, one urban and two rural districts).
- Put codes on the interview piles, first focus group discussions with TB patients in the urban district. Be consistent in your coding system.
- Sort the interviews into two piles per type of district, one for focus group discussions and one for in-depth interviews.
- Read the objectives of the study and try to categorize the responses according to the labels in the Excel spreadsheets. Good examples of spreadsheets for in-depth interviews and focus group discussions are provided on the CD-ROM in this book.
- If you come up with new labels, insert them in the Excel file in the top horizontal row.
- Summarize the responses of each transcript for each label and insert them in the spreadsheet; if there are nice quotations, list them on a separate sheet and link them to your Excel file.
- List the responses for each label in the compilation spreadsheets and add the code of each interview, so that you can refer back to them easily.
- Continue to add the responses to the spreadsheets, until you have filled them all.
- Look at the rows and the columns: now you can compare answers systematically by label.
- Describe the responses for each column by looking at inconsistent and contrasting answers.

- If possible, try to look at the columns in relation to the characteristics of the respondent (age, sex, location).
- Be as systematic as possible and try to draw as many important conclusions as possible.

4. Start analysing and reporting

- Make use of the quotations and answers.
- Describe your findings, by first underlining common findings and then by describing particularly important findings.
- If possible, use quotes to illustrate noteworthy findings.

2.3. How to analyse quantitative data for QUOTE-TB

The following section describes the steps in the analysis of the quantitative research in detail. This may appear rather technical at first reading.

As part of the process of optimization and validation of QUOTE-TB it is important to look at the:

1. Level of the importance ratings,
2. Percentage of valid and relevant answers on each of the quality aspects,
3. Skewness of the answers,
4. Percentage of overlap between the scores on the different quality aspects.

Research teams continuously need to critically examine how each of the quality aspects is formulated.

The following criteria for validation should be used:

1. Importance ratings. When measured on a four-point Likert scale, average importance ratings can be calculated for each quality aspect. These average importance scores range between 1 (all respondents rate the aspect as 'unimportant') and 4 (all respondents rate the aspect as 'extremely important')⁹. The higher the score, the more important this aspect is valued by the respondents and the less reason there is to remove this particular quality aspect from the test version of QUOTE-TB. Ideally, importance scores should be above 2.5 or, in other words, higher than the average. Importance scores can also be viewed by looking at the percentage of respondents that rate a particular aspect as 'extremely important'. This percentage can vary between 0 and 100%. Again, the more important this aspect is valued by the respondents, the less reason there is to remove this particular quality aspect from the test version of QUOTE-TB.
2. Valid and relevant answers. Quality aspects included in QUOTE-TB should be understood by and be valid and relevant for as many TB patients as possible. This means that the percentage of 'missing values'

⁹ Note: The importance ratings in the present version of QUOTE-TB uses a three-point scale, in contrast to the original four point scale. The option "fairly important" was omitted, because during the study and in the analysis it showed no (culturally) significant discrimination to exist between "fairly important" and "important". In the design of QUOTE-TB in other settings, one may opt for either the three or the four point scale.

and percentages of respondents that use the categories 'don't know' should be as low as possible. Percentages of less than 10% missing values and/or less than 30% of the respondents answering 'do not know' are acceptable, assuming that questions are fully understood.

3. Skewness. When four-point Likert scales are used, there is a possibility that 90% or more respondents are only using one category. In this case the assumption of a 'normal distribution' is seriously violated, and factor analyses and reliability analyses are not allowed. Also, if 100% of the respondents indicate that their expectations on a particular aspect are always (or never) met by health care providers, this aspect does not discriminate between the different providers. If expectations are always (or almost always) met, one could consider removing this item from the tool, since there is no room for quality improvement. However, if expectations are never met, this particular aspect should remain in QUOTE-TB. If fewer than 5% of the respondents view the care as 'less than optimal', this particular item can be removed from the questionnaire. If 5 to 10% of the respondents use the extreme category ('always' or 'yes'), the usefulness of this aspect is doubtful.
4. Correlations. The amount of overlap in the answers on different quality aspects can be measured by the correlation between two items. If there is no similarity at all in the answering patterns, Pearson's correlation coefficient is 0; if there is a complete overlap in the answering patterns, Pearson's correlation coefficient will be 1.0. If the Pearson's correlation coefficient is above 0.70, indicating an overlap of approximately 50%, one should consider removing one of the quality aspects from the instrument.

Box 8. Summary of the analysis in the Kenya, Malawi and Uganda study

On a scale between 1 ('not important') and 4 ('extremely important') on average all quality aspects are rated as somewhere between 'important' and 'extremely important'. Mean scores vary between 3.05 ('At the TB facility I should have the same health care provider') and 3.77 ('TB drugs should be available on the day I visit the TB facility'). Percentages of respondents rating the quality aspects as 'extremely important' vary between 47% and 82%. In general, quality aspects that refer to the 'support' dimension received relatively low importance ratings; quality aspects that can be labelled as representing the 'TB-HIV relationship' dimension received the highest importance scores. An overview of the importance scores for all aspects is provided in Annex D: Details of importance scores and ranking.

None of the quality aspects included in section B of the importance part of QUOTE-TB had a number of 'missing values' that exceeded 10%, with the highest percentage of respondents in the 'no answer' category being 1.5%.

Looking at the skewness of the distribution of answers, items 'Do the health providers in this facility tell you that TB can be cured?', 'How often do you have to pay for your TB drugs?', 'How often do you have to pay a tip in order to get your TB services?' and 'How often do you receive transport support from the health facility?' showed high percentages of respondents in the extreme answering categories. Also, some other quality aspects showed percentages of extremely satisfied or dissatisfied respondents between 91% and 95%.

Analysing the performance data, correlation coefficients between the following pairs of items are relatively high ($r > 0.70$): B1-4 and B1-5, B1-6 and B1-7, B4-6 and B4-7, B9-1 and B9-2.

Finally, after this analysis of the data, it is necessary to (1) carry out further explorative factor and reliability analysis, (2) check for internal consistency of the data, and (3) explore the need to reformulate, combine or add items, all in preparation of the final questionnaires.

1. Explorative factor and reliability analysis (see glossary for explanation) should be undertaken to gain insight into the underlying structure (or taxonomy) of the tool, and not primarily to reach a further reduction in the number of quality aspects. This analysis is done in SPSS, using Principle Component Analysis with varimax rotation (see glossary for explanation).
Factor and reliability analyses can be carried out on the performance dataset. Box 10 on page 59 shows the results of these analyses in terms of reliable scales.
2. The quality aspects should then be grouped together in a number of scales or dimensions. The internal consistency or reliability can then be measured by the Cronbach's alpha (α) reliability coefficient, whereby

values between 0.70 and 0.80 are moderate to good, and above 0.80 good to very good. The minimum acceptable value to be able to talk about meaningful correlation is 0.70.

Sometimes scales (Cronbach's alpha coefficients) can be slightly improved by excluding one or two items from each of the scales. Although this might be advisable from a psychometric point of view, it would also mean that quality aspects that are rated by TB patients as 'important' or even 'extremely important' would be left out and, therefore, challenges the validity of the scales and tools. Therefore, these items are highly relevant to incorporate in QUOTE-TB.

An example from the Kenya, Malawi and Uganda study is presented below in Box 9.

Box 9. Example of internal consistency measured by Cronbach's alpha from the Kenya, Malawi and Uganda study

For two of these scales ('availability of TB services' and 'infrastructure') reliability coefficients are between 0.60 and 0.70, indicating that the internal consistency of the items included in the scale is poor to moderate. For another two scales ('information about TB' and 'provider interaction and counselling') internal consistency between the items, as measured by the Cronbach's alpha (α) coefficient, was between 0.70 and 0.80 and, therefore, moderate to good. For the scale with three items about the TB-HIV relationship, the Cronbach's alpha reliability coefficient is 0.83, reflecting an internal consistency which is 'good'.

The reliability coefficient of the 'availability of TB services' scale (α = 0.61) could only slightly be improved to 0.62 or 0.63 by removing one or two items. For the 'infrastructure' scale, the reliability coefficient could be improved to 0.64 by leaving out the item on the presence of comfortable benches.

Examples of quality dimensions (reliability scales) and quality aspects/items after item analyses from the Kenya, Malawi and Uganda study are presented below in Box 10.

Examples of non-scalable separate quality aspects after item selection, item analyses and reformulation of items from the Kenya, Malawi and Uganda study are presented below in Box 11.

Box 10. QUOTE-TB quality dimensions and quality aspects/items after item analyses and item selection (from the Kenya, Malawi and Uganda study)	Item Total correlation	Alpha, if item deleted
Availability of TB services (6 items; $\alpha = .61$)		
• Are the waiting times before being served by providers of this facility acceptable to you?	.48	.49
• How often are you attended by the same health providers in this facility?	.37	.55
• How often are the service hours of this facility convenient for you to get your TB treatment?	.46	.51
• How often are drugs available when you require them?	.28	.59
• How often do you experience difficulties in obtaining TB services in this facility because of language barriers?	.33	.59
• How often do you have to go to another health unit for TB services or treatment?	.17	.62
Information about TB (7 items; $\alpha = .73$)		
• Do the health providers in this facility tell you when you stop spreading TB to others?	.51	.68
• Do the health providers in this facility tell you that TB can be cured?	.13	.74
• Do the health providers in this facility tell you about the importance of observed treatment?	.34	.72
• Do the health providers in this facility tell you about the side effects of TB drugs?	.61	.65
• Do the health providers in this facility tell you about the need for sputum tests at given points during your treatment schedule?	.47	.69
• Do the health providers in this facility tell you about the duration of the TB treatment?	.41	.70
• During your visits to this facility, do health providers tell you about how to store your drugs obtained for your TB treatment?	.56	.66
Provider interaction and counselling (6 items; $\alpha = .73$)		
• During your visits to this facility, how often do the health providers treat you with respect?	.47	.69
• During your visits to this facility, how often do the health providers listen carefully to you?	.52	.67
• During your visits to this facility, how often do the health providers explain things in a way you can understand?	.60	.66
• During your visits to this facility, how often do you have sufficient time to discuss your problems?	.61	.64
• During your visits to this facility, how often is your privacy respected during examination?	.39	.71
• Do health providers at this facility tell you how TB can affect your everyday life?	.32	.75
TB-HIV relationship (3 items; $\alpha = .82$)		
• Did health providers in the facility inform you about the link between TB and HIV?	.72	.72
• Were you informed by the health providers in this facility on how to prevent HIV infection?	.75	.69
• After being diagnosed as a TB patient, were you advised to take an HIV test?	.59	.85
Infrastructure (4 items; $\alpha = .61$)		
• How often is this facility clean?	.54	.50
• Is there safe drinking water in this facility?	.40	.55
• How often are the toilets in this facility usable?	.48	.49
• Are there enough comfortable benches to sit on in this facility?	.29	.64

Box 11. Separate quality aspects in QUOTE-TB after item selection, item analyses and reformulation of items (from the Kenya, Malawi and Uganda study)

Procedures and Tests (7 separate aspects)

- Does this facility offer services to examine your sputum?
- Does this facility offer home-based TB treatment?
- Were you physically examined during your first visit to this TB facility?
- Was your sputum examined when you were diagnosed with TB?
- How many working days were there between your first sputum submission and the time you got your results?
- In case of germs in your sputum that cause TB, were your close contacts examined by the TB facility?
- How often is there a treatment observer checking on your daily intake of TB drugs?

Costs and Payment (3 separate aspects)

- How often do you have to pay a tip in order to get your TB services or treatment?
- How often do costs (e.g. transport) prevent you from getting to your TB facility?

Support (2 separate aspects)

- How often do you receive transport support from the health facility?
- How often do you receive food support from the health facility?

Miscellaneous (1 separate aspect)

- During your visits to this facility, how often do you experience discrimination because you have TB?

3. Finally, research teams should reformulate and add aspects or items to the list during this analysis workshop. These can be added for validity reasons when the answers to the 'open question' for additional quality aspects that are relevant for TB patients suggest so.

Examples of the procedures of reformulation, combination, changing and removal of items from the Kenya, Malawi and Uganda study are presented below in Box 12.

Box 12. Reformulation, combination, changing and removal of items (from the Kenya, Malawi and Uganda study)

Finally, a critical examination of all the 50 quality aspects included in the test versions of QUOTE-TB resulted in suggestions to reformulate items, combine certain overlapping items, change answering categories or remove some redundant items.

Aspects reformulated

- Is your TB facility easy to reach? (Scale: Availability of TB services)
- How often are TB services available during the working hours of this facility? (Scale: Availability of TB services)
- How often are the relevant providers you come to see in this facility available? (Scale: Availability of TB services)
- How often do you have to pay for your regular TB services (e.g. sputum tests, TB drugs, x-rays, etc.) (Scale: Payment)
- Were you informed where to get HIV treatment if you need it? (Scale: TB-HIV relationship)

Aspects added for validity reasons

- During your visits to this facility, how often do the health providers discuss with you how to deal with your problems? (Scale: Provider interaction and counselling)

2.4. How to calculate and interpret performance, importance and quality impact scores

There are different ways to use the rating scores that can be derived from QUOTE-TB. Using the separate parts of the tool, performance and/or importance scores can be calculated on the level of the individual quality aspects or the different quality of TB care dimensions. If there are sufficient respondents, these scores can be broken down by different subgroups of respondents (e.g. men/women, educational level, age category) or TB facility and country characteristics (e.g. urban/rural, hospital/health centre/dispensary, government/private).

Also, it is possible to combine performance and importance ratings into Quality Impact (QI) scores on the aggregated level by multiplying them. These QI scores can be used in projects that aim at selecting and/or improving target areas or specific points of quality of care from the perspective of TB patients.

The quality aspects in Table 1 in Volume 1 are selected to illustrate the use of QUOTE-TB for quality assurance and quality improvement purposes.

There are also different ways to calculate performance and importance scores. If we look at the four-point Likert scales as interval scales with equal distances between the categories, mean scores can be calculated based on the values assigned to each of the answering categories. If these values vary between 1 ('worst possible care') and 4 ('best possible care'), the mean score can also vary between 1 and 4. The higher the mean score, the better the quality of TB care. The underlying assumption for interpreting average scores in a meaningful way is that the original ratings are normally distributed, and that it is a true interval scale¹⁰.

If this assumption is heavily violated, median scores (the point at which 50% of the respondents give higher and 50% give lower ratings), which are less effected by skewed distributions, can be used instead.

There is a third way to calculate aggregated rating scores, which is probably more straightforward to understand, especially when four-point Likert scales are combined with 'yes-no' questions. In this way, different categories are combined in either 'yes' or 'no' (performance scores) or in 'extremely important' versus the rest of the importance categories. To illustrate these different methods and to show how performance and importance scores can

¹⁰ In the present version of QUOTE-TB, the importance score is along a three-point scale. The principle of calculating mean and median scores remains the same.

be combined in QI scores, we will use sample statistics derived from the test version of QUOTE-TB.

For this purpose, we use the 10 selected quality aspects. Table 4 shows performance scores, importance scores and QI scores for these 10 selected quality aspects, whereby:

- N1 and N2 refer to the total number of respondents in the performance data set (**N1**) and in the importance data set (**N2**).
- Mean scores on performance (**P-1**)
- Percentage of respondents in the 'sometimes' and 'never' or 'no' categories on performance (**P-2**)
- Mean scores on importance (**I-1**)
- Percentage of respondents in the 'extremely important' category on importance (**I-2**)
- combination of P-2 and I-2 giving the quality impact (**QI**)

Table 4. Sample statistics (performance scores, importance scores, quality impact scores) based on the tested version of QUOTE-TB.

Quality aspect	N1	N2	P-1	P-2 (%)	I-1	I-2 (%)	QI
A. Acceptable waiting times	343	339	3.07	32.4	3.38	46.6	1.51
B. TB drugs available	318	339	3.52	16.0	3.77	77.9	1.25
C. Information on side effects	345	338	3.11	29.6	3.62	65.1	1.92
D. Respectful attitude	345	339	3.62	10.1	3.68	69.0	0.70
E. Time for discussion	342	338	3.02	33.3	3.56	60.9	2.03
F. Information on TB-HIV link	345	339	3.36	21.4	3.69	70.5	1.51
G. Usable toilets	327	337	3.08	31.5	3.71	73.6	1.71
H. Physical examination	343	337	3.14	28.9	3.65	71.8	2.08
I. Payment of tips	344	339	3.99	1.2	3.64	81.7	0.10
J. Food support	345	339	1.19	94.2	3.19	51.9	4.89

We will explain Table 4 in greater detail. The second column indicates the number of respondents that have rated each of the selected quality aspects. For example: N1 indicates that performance ratings for item B1-1 ('Are the waiting times before being served by providers of this TB facility acceptable for you') are based on the ratings of 343 respondents, while the importance scores for item B1-1 are based on the ratings of 339 respondents (N2). For the 10 items in Table 4, the number of respondents on which the

performance scores are based varies between 318 and 345. For the importance file, the number of respondents varies between 337 and 339.

- The **P-1 scores** are based on the number of respondents that have selected each of the four (or sometimes two) answering categories that are used in the performance questionnaire. For item A, 14 respondents answered that waiting times are never acceptable (score '1'), 97 respondents answered that waiting times are sometimes acceptable (score '2'), 83 respondents answered that waiting times are usually acceptable (score '3'), and 149 respondents answered that waiting times are always acceptable in this facility (score '4'). The average of these scores is 3.07. For items with only two answering categories a 'no' answer receives the score '1', while a 'yes' answer receives the score '4'. In theory, performance scores calculated in this way can vary between 1 (all respondents tick the box 'no' or 'never') and 4 (all respondents tick the box 'yes' or 'always'). For the 10 items in Table 12 the P-1 performance scores vary between 1.19 and 3.99. The score of 1.19 for item J indicates that almost all respondents answered that they don't receive any food support from the TB facility (the exact figures: 318 respondents answered 'never', 7 respondents answered 'sometimes', 2 respondents answered 'usually', and 18 respondents answered 'always'). The score of 3.99 for item B7-2 indicates that all but a few (4 respondents, to be exact) reported that they never had to pay a tip to get their TB services.

In this scenario, a higher score means better performance.

The advantage of this calculation is that it provides more detailed information on performance, as all available answering categories are used.

The disadvantage is the narrow scale (from 1 to 4) and difficulties in interpreting the scores, and difficulties in drawing firm conclusions.

- The **P-2 scores** represent a different way of calculating performance scores. The P-2 score for item A indicates that 32.4% of the respondents answered that they are 'never' or only 'sometimes' faced with acceptable waiting times. The remaining 67.6% answered that waiting times before being served are usually or always acceptable. Although some information is lost because the two positive and the two negative answers are taken together, this way of presenting performance data is easy to use with four- and two-point answering categories and easy to interpret. For the 10 quality aspects in Table 12, performance scores based on the percentages of negative reports vary between 1.2% (item I) and 94.2% (item J).

In this scenario, a higher score means worse performance.

The advantage of this calculation is the ease of computing and understanding the results. Another advantage is the possibility of calculating the QI score in combination with I-2 (see below).

The disadvantage is that some detail is lost, as the four answering categories are collapsed into two.

- The **I-1 scores** are calculated in the same way as the P-1 scores, but now refer to the answering categories that were used in the importance questionnaire. Looking at item A, the data files show that 5 respondents rate this aspect as 'not important' (score '1'), 18 respondents rate this aspect as 'fairly important' (score '2'), 158 respondents rate this aspect as 'important' (score '3'), and another 158 respondents indicate that they find it 'extremely important' that waiting times before being served are acceptable (score '4'). This results in an average score of 3.38. Calculated in this way, the average importance scores for the 10 sample items vary between 3.19 (item J) and 3.77 (item B). For all quality aspects in the tested version of QUOTE-TB, average importance scores vary between 3.05 and 3.77 (see Annex G: Item characteristics, results of the item analyses and inter-item analyses).

In this scenario, a higher score means more important.

The advantage of this calculation is the detailed information on importance, as all available answering categories are used.

The disadvantage is the narrow scale (from 1 to 4) and difficulties in drawing firm conclusions.

- The **I-2 scores**: another way of presenting importance scores is by only looking at the percentages of respondents that are rating an item as 'extremely important'. Especially when there are no (or hardly any) unimportant items included in the list of quality aspects to be rated, working with the percentage in the extreme category (e.g. 'extremely important') provides more insight into the differences in performances scores than working with average scores on a scale of 1 to 4. For item A, the I-2 score of 46.6 indicates that 46.6% of the 339 respondents have rated this particular item as 'extremely important'. For all 10 sample items, percentages of respondents answering 'extremely important' vary between 46.6% and 81.7% (item I).

In this scenario, a higher score means more important.

The advantage of this calculation is the straightforward ease of computing and understanding the results. Another advantage is the possibility of calculating the QI score in combination with P-2 (see below).

The disadvantage is that some detail is lost, as only one answering category ('extremely important') is analysed.

- Finally, the **QI scores**. These scores are derived from combining the P-2 scores and I-2 scores. As an example we look at the QI score for item A. The QI score of 1.51 for this particular item is the result of multiplying the P-2 score with the I-2 score, divided by 1000. Or in figures: $(32.4 \times 46.6)/1000 = 1.51$. For the 10 example items in Table 4 the QI scores vary between 0.10 (item B7-2), which indicates hardly any room for improvement, and 4.89 (item I). The maximum score theoretically possible is 10, indicating that 100% of the patients perceive poor performance of those TB care aspects considered 'extremely important'.

The higher the QI score, the more room or necessity for improvement.

This QI score is an essential element of QUOTE-TB.

Although it is difficult to give exact criteria, in general one might say that QI scores above 1.00 indicate that improvement is possible and may be necessary. This is based on the assumption that generally approximately 70% of respondents will rate the item of the service as important or very important, and also approximately 15% of them will be unhappy with the service ($15\% \times 70\%/1,000 = 1.00$).

2.5. Follow-up research for final validation of QUOTE-TB

With the implementation of the new version of QUOTE-TB in Malawi, Kenya and Uganda, more empirical data will become available. With these additional data it will be possible to explore its psychometric characteristics in greater detail. Also it will be possible to look at its discriminative power and its usefulness in quality improvement projects. Follow-up research can concentrate on four main topics:

- the structure (taxonomy) of QUOTE-TB;
- establishing importance scores for the TB quality aspects on a national level;
- the discriminative power of QUOTE-TB;
- the selection of case mix adjusters when used in large-scale benchmarking studies.

We will elaborate on these four topics further.

Structure of QUOTE-TB

As a result of the process of optimization of QUOTE-TB (see Chapter 2.3 of this volume) a total of 46 quality aspects were selected for inclusion in its present version. Of these, 27 were grouped together in five reliable scales, and the remaining 19 items can be seen as separate quality aspects.

However, during the process of optimization, several adjustments were made to the previous version. The exact wording of seven quality aspects was changed, some answering categories were altered and, based on the answers on an 'open question', one quality aspect was added to the 45 aspects already selected. As a result, it is necessary to re-establish the psychometric characteristics of the present version of QUOTE-TB in terms of reliable scales, inter-item correlations and item non-response. This can be done on the level of the separate countries, as soon as new empirical data based on the present version become available. A minimal data set for these analyses is 150 cases in each of the three countries; data analysis can be done using the SPSS 15.0 computer program.

Importance scores

The present version of QUOTE-TB differs from the previous (test) version that was used in the quantitative test. In addition to the changes in the quality aspects mentioned above, the wording and number of quality dimensions used in a ranking procedure were also changed. As part of the process of testing the new tool, the previous version was completed by a convenience sample of 150 respondents in Kenya and Uganda and a convenience sample of 30 respondents in Malawi. As a result, up to now

there are no representative data available that allow us to establish the importance scores of the 46 aspects included in the present version on a national level.

Implementing the new present version of QUOTE-TB on a national level will also allow us to compile national data on the importance ratings of the 46 quality aspects included. To compile these data, the importance part of the tool has to be completed by a representative, stratified sample of TB patients. Stratification variables are the degree of urbanization (urban versus rural), educational level (none and primary versus secondary and tertiary) and gender. Around 400 completed interviews are necessary in each country. Data analysis can be done using the SPSS 15.0 computer program.

Discriminative power of QUOTE-TB

The development of a new QUOTE-TB consists of three phases:

- 1) A qualitative phase, including a combination of focus group discussions and/or in-depth interviews;
- 2) An initial quantitative test looking at the psychometric characteristics; and
- 3) A second quantitative test looking at the discriminative power of the new tool.

This second quantitative test aims at establishing the usefulness of the new tool in large-scale (national) benchmarking studies, and its ability to establish differences in quality of care between districts and/or facilities. For this final test, empirical data referring to a minimum of 20 different districts and/or facilities (1st level) and 30–50 respondents per district and/or facility (2nd level) are necessary. Implementing the present version of QUOTE-TB in Kenya, Uganda and Malawi on a national scale allows its discriminative power to be tested. Data derived from nationwide studies such as these should be analysed in a multi-level design (preferably using the MLWin computer program). Based on the results of these analyses, it will be possible to decide upon the power of the relevant scales and separate aspects to differentiate between quality of care in different districts and/or facilities.

Selection of case mix adjusters in large-scale benchmarking studies

Quality of care ratings are influenced by respondent characteristics (e.g. their age, level of education, perceived health) and by characteristics related to the facilities that TB patients visit. Regardless of the actual service level, older patients are usually more satisfied with the care they receive than younger patients, while the educational level of the respondent is negatively

related with patient satisfaction scores (the higher the education level of a patient, the lower their level of satisfaction).

To achieve a fair comparison between the different districts and/or facilities in nationwide benchmarking studies, it might be necessary or advisable to adjust the quality of care ratings for some of the respondent characteristics and/or district/facility characteristics. Relevant case mix adjusters can be selected on the basis of the same data set that is used to establish the discriminative power of the present version of QUOTE-TB. Apart from selecting the relevant case mix adjusters, multi-level analysis (using MLWin) allows correction of the data for these variables.

ANNEXES

Annex A. Why this tool? A search through literature

A vast body of literature exists about patient and client satisfaction, and quality of care. Here information from peer-reviewed literature related to these topics is presented.

Quality of care in TB control

Patient satisfaction has been adopted as one of the indicators of quality of care (Sitzia and Wood 1997). Other aspects of quality of care include the performance of standard interventions and the impact of medical treatment. The concept of satisfaction is often defined as the perceived discrepancy between a patient's expectations and actual experience. In some cases satisfaction has been described as a personal evaluation (or rating) of health care services and providers based on personal preferences and expectations (Ware et al 1983). As a result, patient satisfaction ratings are mostly influenced by expectations as well as by patient characteristics (demographic variables such as age and education) and psychosocial variables.

The literature (Girange and Festenstein 1993; Jaramillo 1999) on TB control programmes shows that patient perspectives are often not considered. However, an understanding of patient perspectives is important in ensuring that TB programmes are meaningful and appropriate for TB suspects and patients. The importance of patient perspectives in understanding the potential impact of TB programme reforms, including decentralization, integration of TB and other services, and the evaluation of diagnostic approaches, has been shown (Needham and Bowman 2004). Overall, a patient-centred perspective is central in the design and redesign of control programmes. Given the immense burden of TB borne by patients themselves, control programmes cannot neglect their perspective as a key part of any successful strategy (Needham and Bowman 2004). Patient satisfaction is, therefore, key to quality assurance and the expected outcome of care.

Generic aspects of assessing quality of care

The Donabedian framework is the most frequently applied model for studying quality of care. It underscores the conceptual distinctions between structure, process and outcomes. Structure is the environment in which health care is provided; process is the method by which health care is provided, and outcome(s) as a consequence of the health care provided (Castañeda-Méndez 2005).

Almost all of the recent studies (Mills et al 2004; Needham et al 2003; Westaway et al 2003; Fonn et al 2001; Jitta 1998) of quality of care in health care seem to broadly follow the structural and process approaches to quality evaluation. Westaway et al (2003) – based on Donabedian's model to

identify the underlying interpersonal and organizational dimensions of patient satisfaction for diabetic patients – identified the availability of a seat and a toilet in the waiting area and cleanliness among the organizational dimension of quality of care. Jitta (1998), in a study of quality of services in Uganda, assessed quality in primary curative care based on structural, technical and interpersonal relations in clinics. Under structural quality, the availability of drugs was *inter alia* assessed. Service users valued adequate supplies of drugs as the central element of curative care.

Needham et al (2003) also underline the importance of structural aspects, for instance convenient locations of clinics, availability of anti-TB drugs and other medical supplies for TB care. In addition, they underline the importance of efficient diagnostic services, including microscopes; appropriately trained laboratory and clinical personnel; correct and timely diagnosis; and the availability of a regular quality assurance and monitoring system in place. Needham (2005), in his study in Zambia, reflects travel to clinics as an important structural dimension of quality. He found that patients travelling to seek care spend 16% of their monthly income on transport, and that patients were often tempted to travel if they thought that a more distant facility provided a better service or a more reliable drug supply.

Other studies also highlight specific generic issues relevant in health service provision. This includes access to services, follow-up and continuity mechanisms (Creel et al 2002); language, physical infrastructure including amenities of care such as cleanliness, comfort and privacy; and interpersonal relationships (PAHO 2003).

Patient satisfaction

In 1997 a USA/UK-focused review discussed 100 papers presented in the field of patient satisfaction (Sitzia and Wood 1997). They list three functions that state the importance of measuring patient satisfaction:

- Satisfaction can simply describe health care services from the patient's point of view
- Patient satisfaction may be – in Donabedian's term – thought of as a measure of the 'process' of care
- Evaluation of health care is regarded by many as the most important function of patient satisfaction (Sitzia and Wood 1997: 1830)

They underline that patient satisfaction has been valuable in all four fields of evaluation as distinguished by Coulter (Sitzia and Wood 1997: 1830):

- Evaluation of specific treatments (drug therapies for surgical procedures)

- Evaluations of patterns of care for particular groups
- Evaluation of organizations (hospitals, clinics)
- Evaluation of health systems (different models of health care delivery)

Important criteria for the determination of patient or client satisfaction are effectiveness, efficiency and equality; social acceptability and the structure process; and an outcome approach as the evaluation of health care. Others mentioned equity, accessibility, acceptability, efficiency, effectiveness and appropriateness as important dimensions (Redfern and Norman 1990).

Donabedian defined 'outcome' as the most important aspect of client satisfaction, being a change in a patient's current and future health status that can be confidently attributed to antecedent care (Sitzia and Wood 1997: 1830). Scientific debates exist on whether observed outcomes of care are attributed to care alone, because social, economic and other factors can influence the course of an illness. In quality assurance and in health care, quality appears to be seen as quite a subjective entity. Sitzia and Wood underline Ware's distinction between objective satisfaction reports about providers and care, such as waiting time and satisfaction ratings that reflect three variables: the personal preferences of the patient, the patient's expectations, and the realities of the care received. A satisfaction rating is both a measure of care and a reflection of the respondent. In this way of thinking 'patient variables' are referred to as determinants of satisfaction, while care variables are the components of satisfaction.

In general, different determinants of satisfaction are identified, namely expectations of the patients, the characteristics of the patients, and the quality and condition provided by the TB services.

Determinants of patient satisfaction:

1. Expectations

When patients' expectations are met by high-quality care, the satisfaction level rises. One may distinguish between background expectations, interaction expectations and action expectations to be divided into ideal and actual expectations (Sitzia and Wood 1997: 1835). Expectations may also vary according to knowledge and prior experiences, i.e. raising quality of care raises expectations and may result in gradually lower levels of satisfaction.

2. Patient characteristics

Satisfaction with health care may depend upon variables such as social class, marital status, gender and age. However, many authors acknowledge the minor influence of these characteristics, seeing age as the most dominant one (Sitzia and Wood 1997: 1835). In general, one may argue

that younger people are less satisfied with primary care and are less compliant to prescriptions. The higher the level of education of the patient, the less satisfied he/she is; gender, ethnicity and so on do not show a clear relationship to levels of satisfaction.

3. Quality aspects

Ware et al (1983) have presented dimensions taken up by many other studies and proving that satisfaction is a multi-dimensional construct:

- Interpersonal features of the way providers interact with patients (respect, concern, friendliness, courtesy)
- Technical quality of care
- Accessibility/convenience factors
- Financial factors
- Efficacy/outcomes of care
- Continuity of care
- Physical environment

Thus, satisfaction is a multi-dimensional concept encompassing a number of components including interpersonal manner, technical quality of care, accessibility/convenience, efficacy/outcome of care, continuity of care, physical environment, availability of services and patient education/information. Individuals tend to evaluate distinct aspects of their care when making an overall evaluation of (parts of) the health care system (Sixma et al 1998).

From a meta-analysis of 221 studies (Sixma et al 1998) on patient satisfaction, it appeared that the most important dimensions of quality for the patient consisted of a core of 11 desired factors, in order of importance:

1. Humaneness (65% of all studies)
2. Informativeness (50%)
3. Overall quality of care (45%)
4. Technical competence or skills of the provider (43%)
5. Bureaucratic procedures (28%)
6. Accessibility and availability of services (27%)
7. Costs of treatment and flexibility of payment mechanisms (18%)
8. Comfort of the setting, attractiveness, quietness, neatness of health facilities (16%)
9. Continuity of care (6%)

10. Effective and useful outcome of health care process (4%)

11. Attention to psycho-social problems (3%)

In a literature review of 17 studies in African countries and Indonesia, similar factors were identified although not ranked in order of importance (Brawley 2000). Two studies on leprosy patient satisfaction to improve quality in Nepal and Brazil (Van Dijk et al 2003; Van Dijk 2002) also mentioned similar factors and some setting- and disease-specific factors as well, such as the time and costs spent to reach the clinic, and stigma attached to disabled leprosy patients. However, it can be anticipated that importance ratings assigned to these quality of care dimensions will differ between nations, depending on the prevalent health care system, cultural values and the economic situation within a country and/or its inhabitants. Also, it can be anticipated that the way these basic quality of care dimensions are operationalized differs from country to country, from district to district and from patient group to patient group.

Competence and technical capabilities

Staff competence implies that staff must be able to do what is needed, including having the skills to know what patients need and to treat them with respect (PAHO 2003). Jitta (1998) found that limited technical capabilities (examination, diagnosis, and prescription) of health providers were mentioned as a quality concern. In their study in South Africa, Mills et al (2004) found that views on attitudes and competence of service providers ranged across a spectrum from excellent to unacceptable.

Patient-provider relationship

A successful TB treatment programme involves delivering skilled patient counselling and support within a patient-centred approach to empower patients to work through individual decision-making processes and overcome barriers to treatment completion (Watkins and Plant 2004). However, the Jitta (1998) study on quality of health care in Uganda found that very little counselling and supportive care – such as nutritional information – was given to patients, and little explanation was offered to patients on the nature of their problem.

Studies on clinic staff perceptions of TB treatment delivery have shown that staff members do not have shared understandings of the difficulties and priorities in TB treatment. In a study in Bali, Indonesia (Watkins and Plant 2005), the main areas of difference in staff perceptions concerned the existence of barriers to treatment and the focus on the community context of TB treatment. Findings suggested that not all prevalent perspectives of TB treatment delivery among staff working in TB control were well aligned with the provision of a supportive patient-centred approach. It is, however,

important to identify the most effective means of facilitating a more supportive patient-centred approach to TB treatment delivery.

The concept of the patient-provider relationship is relevant in virtually all types of TB-related health care (Bruce, 1996). From a human welfare perspective, all patients, no matter how poor, deserve courteous treatment (Williams et al 2000). A study on the quality of health care in Uganda (Jitta 1998) assessed interpersonal quality based on courtesy and concern shown by staff, the provider making the patient comfortable, allowing the patient to explain adequately their illness and explaining the diagnosis and treatment to patients. The study observed an attitude of superiority shown by providers when dealing with the illiterate population, assuming that patients would not understand detailed explanations.

Similarly, Johansson et al (2000) – in their study on gender and TB in Vietnam – reported that staff attitudes and the quality of health services were not always corresponding to people's expectations of appropriate health services. A study in South Africa found that public nurses in large urban clinics were criticized for their attitude and treatment of patients, rudeness, lack of confidentiality and blatant favouritism towards patients they knew or perceived to be better-off. However, the attitudes of staff in other private facilities were barely criticized (Mills et al 2004). Scott et al (1995: 81) suggest that bad attitudes could be resolved if health services are 'organized and administered in ways that ensure ordinary caregivers, especially those who may not be exceptionally caring and compassionate by temperament, will nevertheless be provided with opportunities, skills, and contexts that allow them to deal with their patients in caring and compassionate ways'.

Westaway et al (2003) identified support, consideration, friendliness, and encouragement as key interpersonal dimensions. PAHO (2003) and Helman (2001) characterize good interpersonal relationship skills as effective listening and communication attitudes of providers, the establishment of trust, respect, responsiveness and confidentiality.

The literature highlights specific confidentiality issues that require special attention by health care providers working with TB patients. Great care must be taken to ensure that patients' rights, especially the right to privacy, are protected to the fullest extent possible, so that the patient-provider relationship is not compromised.

Helman (2001) discusses the importance of internal and external context in mediating patient-provider interaction. The internal context pertains to the prior experiences, expectations, cultural assumptions, explanatory models and prejudices (based on social, gender, religious or racial criteria) that each party brings to the clinical encounter. The external context includes the actual setting in which the encounter takes place, such as a hospital, clinic

or doctor's office, and the underlying social influences acting upon the two parties. These include the dominant ideology, religion and economic system of the society, as well as its class, ethnic divisions and gender.

Gender issues

Recognition of a gendered nature of health care systems has increasingly become relevant in refining the patient-provider interpersonal relationship (Creel 2002; Hartigan 2001; Thorson and Johansson 2004). Although there are apparently no existing studies in Uganda that link gender and quality of care in TB service delivery, other studies carried out in Uganda and elsewhere are important in understanding the relevance of gender issues in delivering high-quality TB services. In a multi-country study carried out in five countries including Uganda, the met and unmet needs of women using health services and obstacles to accessing good-quality care were explored (Fonn et al 2001). A study by Hartigan (2001) suggests that the gendered nature of the health system highlights the need to sensitize health workers to the needs of female patients.

In their studies in Vietnam, Thorson and Johansson (2004) and Johansson et al (2000) suggest that gender equity should be the guiding principle for the TB patient-doctor encounter. Thorson and Johansson (2004) found that perception and attitudes to TB were different between men and women. Female TB patients were more likely to perceive stigma and severe consequences of TB than men. In an earlier study, Johansson et al (2000) reported that women saw themselves and were seen by others as being more sensitive to poor service conditions and staff attitudes than men. Thorson and Johansson (2004) further reported that women were lost or delayed within the health care-seeking chain, mainly because of barriers associated with female gender. They found that gender characteristics were generally considered as being capable of causing a longer delay among women in following the doctor's prescribed investigations such as chest radiographs or sputum smear investigations. In addition, where resources were scarce, the allocation of funding for women's illnesses were even less than the small amount available for men. They reckoned that, although barriers were identified, patient-doctor encounters seem to be steered by an equality principle that results in gender blindness, since equal treatment is suggested despite the different gender needs.

Linguistic barriers to care

The issue of language is critically relevant in the patient-provider relationship, since clinical consultations are usually conducted in a mixture of everyday and medical jargons, which could be unfamiliar to the lay public. The use of the same terminology by doctor and patient is not a guarantee of mutual understanding, especially where the clinician has a different social or cultural background (Helman 2001). Clearly, good quality of care implies

removal of linguistic barriers (PAHO 2003) so that medical treatment can make sense and thus is acceptable to patients.

In the face of gender, suffering and pain, men are usually expected to have an unemotional 'language of distress', to be stoic and thus to have a high threshold for consultation with a doctor or other health professionals (especially if they are also male). In many cases this stoicism may be counterproductive to health, as it may lead some men to ignore early symptoms of serious disease or the provider to underestimate the seriousness of that disease. However, women contrastingly tend to have a low threshold for consultation with a doctor and display a more emotional 'language of distress' (Helman 2001). This language can lead to misdiagnosis, especially by male doctors who may misinterpret it.

Waiting time

The goal of a high-quality health care system is to ensure timely and efficient use of all available resources (PAHO 2003). Studies (Watkins and Plant 2004; Jitta 1998) show that service users are often dissatisfied with waiting times. In a study exploring treatment-seeking behaviour among people with TB in Bali, Indonesia, Watkins and Plant (2004) found that participants reported frequent delays in obtaining adequate treatment. Further, in her study in Uganda, Jitta (1998) reveals that longer opening hours and limited waiting time make private clinics more accessible. In their assessment of technical quality of care, Mills et al (2004) found that public clinics in South Africa scored well in physical infrastructure and environment but suffered from long waiting times, shorter consultation times and excessive workload. Private clinics scored highly, not only on short waiting times and longer consultation times but also on greater politeness of staff and cleaner facilities.

TB and HIV

Another related issue that has a major impact on the quality of TB services and the perspectives and problems of patients is the prevalence of HIV infection among TB patients. The diseases of HIV/AIDS and TB are inextricably linked: TB accelerates the course of HIV infection and is the leading cause of death among people living with HIV/AIDS (PLWHA); HIV fuels the TB epidemic through the reduction of immunity. Up to a third of all new TB patients in sub-Saharan Africa are dually infected with HIV (Vassall et al 2006). Globally there are more than 14 million people dually infected with TB and HIV (Hussain et al 2007). Perceived and enacted stigma by patients and health providers alike may influence the quality of care of services. As a result of the dual infection, a public and private mix of services becomes necessary to ensure greater equity in access to health services and the continuity of care of patients with infectious diseases (Sheikh et al 2006).

Patient perspectives

Watkins and Plant (2004) admit that barriers to the successful treatment of TB may be associated with individual patient characteristics. Marked stigma has been associated with the abandonment of treatment. A study among the Zulu in South Africa observed that saying TB patients were infectious was tantamount to labelling them as witches or sorcerers, since these are the only people in the community with the power to cause illness to other people. Another study in Mexico City showed that 52% of TB patients discharged from hospital after treatment were not allowed to go home due to the hostility of their families. It also showed that many patients abandoned their treatment early due to costs of transport to the clinic and fear of rejection by their families (Helman 2001). Studies on non-adherence from a patient's perspective should look at the meaning of medication in people's everyday lives, and at the reasons why people take their medication or why they do not (Hardon et al 2004). Watkins and Plant (2004) argue on this subject that lay beliefs and experiences, which are grounded in the social and economic contexts of people's lives, have been found to influence treatment compliance. What appears to be non-adherence from a medical perspective may in fact be a form of asserting self-control over one's disorder. Other reasons for failure relate to the health care system itself, for instance systems failure to elicit reasons for non-adherence (Watkins and Plant 2004), and the ways that clinics are organized. Arranging appointments at times that are not convenient; repetitive registration of patients at each visit; seating people in overcrowded and poorly ventilated waiting rooms; seeing patients rigidly in order of registration and ignoring any extenuating circumstances, may all contribute to people's reluctance to come to the clinic for treatment or follow-up (Helman 2001).

Presently, we still do not know a lot about the actual perspectives of TB patients, as these are not studied very often. One may distinguish among perspectives on their illness, the disease itself and the services provided.

An example is the study by Rajeswari et al (2005), an assessment of patient perspectives in South India about their illness, their reaction to their diagnosis and the impact of the disease on their lives. One of their findings is that perceived stigma remains even after patients achieve clinical and bacteriological cure. One of the causes is poor awareness of the etiology, symptoms and curability of the disease. Educating Directly Observed Treatment Short Course (DOTS) providers and utilizing their services to counsel patients is one of the outcomes of this study (Rajeswari 2005:1851).

In Pakistan, a small-scale qualitative study explored the extent to which factors related to the individual, the care provision process and the cultural context influence the behaviour of patients attending TB clinics in rural Pakistan. Patients were dissatisfied with the care provided, reporting problems with accessing the services, and the main cause being treatment

provision. The patients received too little or false information about TB and did not receive the free drugs they needed for treatment (Khan et al 2000).

A study in Botswana including 212 patients with smear positive pulmonary TB concludes that it is essential for health workers and their health education messages to have knowledge about local beliefs on TB. Although the majority of the patients attend modern health facilities, half of them continued traditional medicine after diagnosis. Ideas of 'pollution' and not knowing anything about the cause, care and cure of the disease may lead to delay and defaulting from the treatment regimen (Mazonde 1999).

In Orissa, a five-week study held 219 interviews with local people in four districts about their perceptions of services and utilization patterns. It seemed that choice of a provider was related to reputation, cost and ability to physically access care providers. Perceived poor quality of services was mainly due to the absence of drugs and the non-availability of staff; these high levels of dissatisfaction lead to higher use of hospitals and private practitioners (Ager and Pepper 2005).

It is clear from the above that there is not much evidence of real patient perspective and satisfaction with the care delivered, and there are many references to side-tracks related to quality of care and patients. Donabedian suggests that quality is not only a measurable entity, but also different perspectives place it along a continuum of valued outcomes (Mackay 2001). Ever since the Donabedian model came into existence there have been advances in understanding patients, for instance through anthropological theoretical models and methodologies (Hardon et al 1994; Helman 2001), which have also instigated a need for appropriate tools to specifically measure quality of care from a patient's perspective.

To conclude: why use QUOTE-TB to assess the quality of TB care from a patient's perspective?

Although a number of studies have investigated patient perceptions of TB treatment delivery (Watkins and Plant 2004), this type of literature hardly exists for specific countries and settings. There is a rising body of most often qualitative studies that assess community, patient or client satisfaction (Gilson et al 1994; Demissie et al 2003) or that measure patient-centred communication in patient and provider consultation (Epstein et al 2005). Mead and Bower (2004) describe the advantages and disadvantages of alternative forms of measurement in which the bio-psychosocial perspective, the 'patient as a person', sharing power and responsibility, the therapeutic alliance and the doctor as a person are mentioned as key dimensions of patient-centredness. They conclude that there are only two approaches to measurement, namely self-report instruments and external observation methods.

The shortcoming in most client or patient satisfaction tools (Van Dijk 2002) is that they are often either research or situation analysis tools that are not operationalized to dimensions to be used by providers and planning. The recent awareness that for measurement the communication behaviour of patients and providers is crucial, as well as the context in which they operate, can only be praised (Epstein et al 2005), but it is accompanied by many warnings that caution should be used in interpreting patient ratings and especially in validating these ratings. Most published measures have face validity, but many lack adequate validation (Epstein 2005:1524). Moreover, ranking is a method used that is often criticized for the tendency of patients to withhold their critical comments (Berhart et al 1999).

The QUOTE architects question the validity and reliability of those other tools, for instance exit interviews, in measuring the quality of health care using indicators such as patient satisfaction, which often score unvaryingly high levels of satisfaction (Hekkink et al 2003). This criticism of other tools is also evident in other studies. One study (Williams et al 2000) which used the exit interview tool found that patients generally were highly satisfied with the services they received; for the large majority of questions more than 95% of respondents said they were pleased with the services they received. In another study, Macnee (2000) examined the results of a study to develop a tool for measuring satisfaction in homeless individuals and found that what constitutes satisfaction and, therefore, quality may not be consistent across populations. Clearly the QUOTE tools do not consider quality as a merely abstract concept reflected in an indicator. Rather, it is experienced as a tangible and personal experience for patients, their families and communities, often with life or death consequences (PAHO 2003).

Patient satisfaction is regarded a multi-dimensional concept, based on the relationship between experiences and expectations. A more fruitful approach than measuring patient satisfaction is to look at the basic components of expectations and experiences. The QUOTE method is based on the sequence of importance, performance, impact (Hekkink et al 2003).

It is within this context that the development of QUOTE has to be valued. As this tool is measuring quality of care from a patient's perspective in a disease- and setting-specific way, some of the shortcomings of other tools and studies are eliminated. Then also the process of the development of the tool implies qualitative and quantitative research as well as testing for validity and validation. Then the results of rating and ranking procedures are prioritized in such a way that policy planners can do something with it, since they receive a ranked outcome of priority areas to be improved by the health system and the providers.

Annex B. QUOTE-TB Performance

QUOTE-TB/performance

Code number: / / /

QUOTE-TB

PART 1 PERFORMANCE

PATIENT INTERVIEW & INSTRUCTIONS

The QUOTE-TB questionnaire is being developed by the Regional Centre for Quality of Health Care (RCQHC) and National TB Programmes (NTPs) of Uganda, Kenya, and Malawi, with technical support from Royal Tropical Institute (KIT), KNCV Tuberculosis Foundation and the Netherlands Institute for Health Services Research (NIVEL) and financial support from USAID/REDSO and DGIS.

Instructions to the interviewer

When a patient has finished his/her consultation with the clinic staff, ask him/her if he/she is aware of being a TB patient, and willing to answer questions about the quality of TB services he/she has received. The interview will take between 10 and 20 minutes. The TB patient should be known to have TB for at least 2 weeks. It is essential that you gain his/her informed consent before beginning the interview, so the following introduction should be given.

Greet the patient

"Hello. My name is

I am interested in what you think about the services provided at this health facility. Your views and opinions are very important to further improve TB services. I would like to ask you questions about your visits to this health facility and the health providers that work in this facility. I would be very grateful if you could spend some time talking with me. I will not write down your name, and everything you tell me will be kept strictly confidential. Your participation is voluntary, and you are not obliged to answer any questions you do not want to. Participating in this interview will not negatively affect the subsequent services you will get. Do I have your permission to continue?"

If no > stop the interview, thank the patient, note 'one refusal' on the non-respondent form, wait for another patient

If yes > continue with the interview. Note: only interview adult patients at least 2 weeks on treatment.

Tick this box whether the patient is a defaulter or not ¹ Yes ² No

Name Interviewer	
Date of interview	
Time interview starts	
Interview conducted in:	Specify language.
Interview conducted at:	Clinic: ¹ <input type="checkbox"/> Yes ² <input type="checkbox"/> No Community, specify where:.....

SECTION A: SOCIO-DEMOGRAPHIC CHARACTERISTICS AND GENERAL QUESTIONS

1. **Patient's sex** ¹ Male ² Female
2. **Patient's age** years
3. **What is your highest level of education?**
- ¹ None
- ² Primary (Standard 1-5)
- ³ Primary (Standard 6-8)
- ⁴ Secondary
- ⁵ Tertiary
- ⁶ Other:
4. **What is the main source of your livelihood?**
-
5. **Before you were diagnosed, what did you do first to get rid of your illness?**
- ¹ None
- ² Self-medication
- ³ Traditional healers
- ⁴ Herbal medicine/therapy
- ⁵ Other, specify:
- ⁶ More than one action
6. **When did your symptoms start? (write response in dotted space below)**
-
7. **After what period did you first go to a health facility**
(probe the time lapse between the onset of symptoms and the first time patient went to a public or private health provider/health facility)? (write response in dotted space and also check the corresponding option below)
-
- ¹ Within one (1) week
- ² Between one (1) and four (4) weeks
- ³ Between four (4) and eight (8) weeks
- ⁴ More than eight (8) weeks
8. **When were you diagnosed with TB for this illness?**
(write response in dotted space and also check the corresponding option below)
-
- ¹ Within three (3) weeks after the onset of symptoms
- ² Three (3) to eight (8) weeks after the onset of symptoms
- ³ More than eight (8) weeks after the onset of symptoms
9. **After diagnosis, when did you start taking the TB treatment?**
- ¹ Within two (2) days
- ² Within one (1) week
- ³ More than one (1) week
10. **What was/were the reason(s) for your visit today? (Multiple answers possible)**
- ¹ Diagnosis, specify:
- ² Drug collection, specify:
- ³ Information/advice, specify:
- ⁴ Follow up sputum examination
- ⁵ Other, specify:

SECTION B : PERFORMANCE OF THE FACILITY

The next part of the survey is about the quality of TB care that you received during your visits to this facility. Please answer the questions in this part of the survey about this facility only. Do not include any other facilities in your answer.

B-1 : AVAILABILITY OF TB SERVICES

First, I would like you to rate nine aspects that have to do with the availability of TB services.

1. Are the <u>waiting time(s) before being served</u> by providers of this facility acceptable to you?	¹ <input type="checkbox"/> Never ² <input type="checkbox"/> Sometimes ³ <input type="checkbox"/> Usually ⁴ <input type="checkbox"/> Always
2. How often are you attended to by the <u>same health provider</u> in this facility?	¹ <input type="checkbox"/> Never ² <input type="checkbox"/> Sometimes ³ <input type="checkbox"/> Usually ⁴ <input type="checkbox"/> Always
3. How often are the <u>service hours</u> of this facility <u>convenient</u> for you to get your TB treatment?	¹ <input type="checkbox"/> Never ² <input type="checkbox"/> Sometimes ³ <input type="checkbox"/> Usually ⁴ <input type="checkbox"/> Always
4. How often are <u>drugs available</u> when you require them?	¹ <input type="checkbox"/> Never ² <input type="checkbox"/> Sometimes ³ <input type="checkbox"/> Usually ⁴ <input type="checkbox"/> Always
5. How often do you experience <u>difficulties in obtaining TB services</u> in this facility because of language barriers?	¹ <input type="checkbox"/> Never ² <input type="checkbox"/> Sometimes ³ <input type="checkbox"/> Usually ⁴ <input type="checkbox"/> Always
6. How often do you have to go (without referral) to <u>another health unit</u> for TB services or treatment?	¹ <input type="checkbox"/> Never ² <input type="checkbox"/> Sometimes ³ <input type="checkbox"/> Usually ⁴ <input type="checkbox"/> Always
7. Is your TB facility <u>easy to reach</u> (distance)?	¹ <input type="checkbox"/> Yes ² <input type="checkbox"/> No
8. How often are <u>TB services available</u> during the working hours of this facility?	¹ <input type="checkbox"/> Never ² <input type="checkbox"/> Sometimes ³ <input type="checkbox"/> Usually ⁴ <input type="checkbox"/> Always
9. How often are the relevant <u>providers</u> you come to see in this facility <u>available</u> ?	¹ <input type="checkbox"/> Never ² <input type="checkbox"/> Sometimes ³ <input type="checkbox"/> Usually ⁴ <input type="checkbox"/> Always

B-2 : INFORMATION

Next, I would like you to rate seven items that have to do with information about TB and its treatment.

1. Do the health providers in this facility tell you when you <u>are not anymore spreading TB to others</u> ?	¹ <input type="checkbox"/> Yes ² <input type="checkbox"/> No
2. Do the health providers in this facility tell you that <u>TB can be cured</u> ?	¹ <input type="checkbox"/> Yes ² <input type="checkbox"/> No
3. Do the health providers in this facility tell you about the importance of <u>observed treatment</u> ?	¹ <input type="checkbox"/> Yes ² <input type="checkbox"/> No
4. Do the health providers in this facility tell you about the <u>side effects</u> of TB drugs?	¹ <input type="checkbox"/> Yes ² <input type="checkbox"/> No
5. Do the health providers in this facility tell you about the need for <u>sputum tests</u> at given points during your treatment schedule?	¹ <input type="checkbox"/> Yes ² <input type="checkbox"/> No
6. Do the health providers in this facility tell you about the <u>duration</u> of the TB treatment?	¹ <input type="checkbox"/> Yes ² <input type="checkbox"/> No
7. During your visits to this facility, do health providers tell you about how to <u>store your drugs</u> obtained for your treatment?	¹ <input type="checkbox"/> Yes ² <input type="checkbox"/> No

B-3 : PATIENT – PROVIDER INTERACTION AND COUNSELLING

Next, I would like you to rate eight aspects that have to do with the interaction between TB patients and health care providers.

1. During your visits to this facility, how often does the health provider treat you with <u>respect</u> ?	¹ <input type="checkbox"/> Never ² <input type="checkbox"/> Sometimes ³ <input type="checkbox"/> Usually ⁴ <input type="checkbox"/> Always
2. During your visits to this facility, how often does the health provider <u>listen carefully</u> to you?	¹ <input type="checkbox"/> Never ² <input type="checkbox"/> Sometimes ³ <input type="checkbox"/> Usually ⁴ <input type="checkbox"/> Always
3. During your visits to this facility, how often do health providers <u>explain things</u> in a way you can understand?	¹ <input type="checkbox"/> Never ² <input type="checkbox"/> Sometimes ³ <input type="checkbox"/> Usually ⁴ <input type="checkbox"/> Always
4. During your visits to this facility, how often do you have <u>sufficient time to discuss</u> your problems?	¹ <input type="checkbox"/> Never ² <input type="checkbox"/> Sometimes ³ <input type="checkbox"/> Usually ⁴ <input type="checkbox"/> Always
5. During your visits to this facility, how often do health providers discuss with you how to <u>deal with your problems</u> ?	¹ <input type="checkbox"/> Never ² <input type="checkbox"/> Sometimes ³ <input type="checkbox"/> Usually ⁴ <input type="checkbox"/> Always
6. During your visits to this facility, how often do you experience <u>discrimination</u> because you have TB?	¹ <input type="checkbox"/> Never ² <input type="checkbox"/> Sometimes ³ <input type="checkbox"/> Usually ⁴ <input type="checkbox"/> Always
7. During your visits to this facility, how often is your <u>privacy</u> respected during examination?	¹ <input type="checkbox"/> Never ² <input type="checkbox"/> Sometimes ³ <input type="checkbox"/> Usually ⁴ <input type="checkbox"/> Always
8. Do health providers at this facility tell you how TB can <u>affect your every day life</u>	¹ <input type="checkbox"/> Yes ² <input type="checkbox"/> No

B-4 : TB – HIV RELATIONSHIP

Next, I would like you to rate four aspects that have to do with TB and HIV.

1. Did health providers in the facility inform you about the <u>link between TB and HIV</u> ?	¹ <input type="checkbox"/> Yes ² <input type="checkbox"/> No
2. Were you informed by the health providers in this facility on how to <u>prevent HIV infection</u> ?	¹ <input type="checkbox"/> Yes ² <input type="checkbox"/> No
3. After being diagnosed as TB patient, were you advised to take an <u>HIV test</u> ?	¹ <input type="checkbox"/> Yes ² <input type="checkbox"/> No
4. Were you informed where to get <u>HIV-treatment</u> in case you may might need this?	¹ <input type="checkbox"/> Yes ² <input type="checkbox"/> No ⁹ <input type="checkbox"/> not applicable

B-5 : INFRASTRUCTURE

Next, I would like you to rate four aspects that have to do with the infrastructure of the TB facility you are visiting.

1. How often is this facility clean?	¹ <input type="checkbox"/> Never ² <input type="checkbox"/> Sometimes ³ <input type="checkbox"/> Usually ⁴ <input type="checkbox"/> Always
2. Is there <u>safe drinking water</u> in this facility?	¹ <input type="checkbox"/> Yes ² <input type="checkbox"/> No
3. How often are the <u>toilets</u> in this facility usable?	¹ <input type="checkbox"/> Never ² <input type="checkbox"/> Sometimes ³ <input type="checkbox"/> Usually ⁴ <input type="checkbox"/> Always
4. Are there enough <u>comfortable benches</u> to sit on in this facility?	¹ <input type="checkbox"/> Yes ² <input type="checkbox"/> No

B-6 : PROCEDURES AND TESTS

Next, I would like you to rate seven aspects that have to do with TB procedures and tests.

1. Does this facility offer services to <u>examine your sputum</u> ?	¹ <input type="checkbox"/> Yes ² <input type="checkbox"/> No
2. Does this facility offer <u>home based TB treatment</u> ?	¹ <input type="checkbox"/> Yes ² <input type="checkbox"/> No
3. Were you <u>physically examined</u> during your first visit to this TB facility?	¹ <input type="checkbox"/> Yes ² <input type="checkbox"/> No
4. Was your <u>sputum examined</u> when you were diagnosed with TB?	¹ <input type="checkbox"/> Yes ² <input type="checkbox"/> No
5. How many <u>working days</u> were there between your first sputum submission and the time you got your results?	¹ <input type="checkbox"/> 0 – 2 working days ² <input type="checkbox"/> 3 – 5 working days ³ <input type="checkbox"/> more than 5 working days
6. In case germs that cause TB were found in your sputum, were your close <u>contacts examined</u> by the TB facility?	¹ <input type="checkbox"/> Yes ² <input type="checkbox"/> No
7. How often is there a <u>treatment observer</u> checking on your daily intake of TB drugs?	¹ <input type="checkbox"/> Never ² <input type="checkbox"/> Sometimes ³ <input type="checkbox"/> Usually ⁴ <input type="checkbox"/> Always

B-7 : COSTS AND PAYMENT

Next, I would like you to rate three aspects that have to do with the costs of TB services.

1. How often do you <u>have to pay for your regular TB-service</u> (e.g. sputum tests, TB-drugs, etc.)?	<input type="checkbox"/> ¹ Never <input type="checkbox"/> ² Sometimes <input type="checkbox"/> ³ Usually <input type="checkbox"/> ⁴ Always
2. How often do you have to <u>pay a tip</u> in order to get your TB services?	<input type="checkbox"/> ¹ Never <input type="checkbox"/> ² Sometimes <input type="checkbox"/> ³ Usually <input type="checkbox"/> ⁴ Always
3. How often do <u>costs (e.g. transport)</u> prevent you from getting to your TB facility?	<input type="checkbox"/> ¹ Never <input type="checkbox"/> ² Sometimes <input type="checkbox"/> ³ Usually <input type="checkbox"/> ⁴ Always

B-8 : SUPPORT

To conclude this rating exercise, I would like you to rate two aspects that have to do with the support received from the TB facility you are visiting.

1. How often do you receive <u>transport</u> support from the health facility?	<input type="checkbox"/> ¹ Never <input type="checkbox"/> ² Sometimes <input type="checkbox"/> ³ Usually <input type="checkbox"/> ⁴ Always
2. How often do you receive <u>food</u> support from the health facility?	<input type="checkbox"/> ¹ Never <input type="checkbox"/> ² Sometimes <input type="checkbox"/> ³ Usually <input type="checkbox"/> ⁴ Always

SECTION C: OVERALL RATING of THE FACILITY

Finally, we would like to know what you think about the quality of care that TB patients receive at this facility

<p>1. We would like to know your overall rating for this TB facility. Using any number from 0 to 10, where 0 is the worst and 10 is the best TB facility possible, what number would you use to rate this TB facility?</p>	<table> <tr><td><input type="checkbox"/></td><td>0 Worst TB facility</td></tr> <tr><td><input type="checkbox"/></td><td>1</td></tr> <tr><td><input type="checkbox"/></td><td>2</td></tr> <tr><td><input type="checkbox"/></td><td>3</td></tr> <tr><td><input type="checkbox"/></td><td>4</td></tr> <tr><td><input type="checkbox"/></td><td>5</td></tr> <tr><td><input type="checkbox"/></td><td>6</td></tr> <tr><td><input type="checkbox"/></td><td>7</td></tr> <tr><td><input type="checkbox"/></td><td>8</td></tr> <tr><td><input type="checkbox"/></td><td>9</td></tr> <tr><td><input type="checkbox"/></td><td>10 Best TB facility possible</td></tr> </table>	<input type="checkbox"/>	0 Worst TB facility	<input type="checkbox"/>	1	<input type="checkbox"/>	2	<input type="checkbox"/>	3	<input type="checkbox"/>	4	<input type="checkbox"/>	5	<input type="checkbox"/>	6	<input type="checkbox"/>	7	<input type="checkbox"/>	8	<input type="checkbox"/>	9	<input type="checkbox"/>	10 Best TB facility possible
<input type="checkbox"/>	0 Worst TB facility																						
<input type="checkbox"/>	1																						
<input type="checkbox"/>	2																						
<input type="checkbox"/>	3																						
<input type="checkbox"/>	4																						
<input type="checkbox"/>	5																						
<input type="checkbox"/>	6																						
<input type="checkbox"/>	7																						
<input type="checkbox"/>	8																						
<input type="checkbox"/>	9																						
<input type="checkbox"/>	10 Best TB facility possible																						
<p>2. Would you <u>recommend</u> this facility to your friends and family?</p>	<table> <tr><td><input type="checkbox"/></td><td>Definitely no</td></tr> <tr><td><input type="checkbox"/></td><td>Probably no</td></tr> <tr><td><input type="checkbox"/></td><td>Probably yes</td></tr> <tr><td><input type="checkbox"/></td><td>Definitely yes</td></tr> </table>	<input type="checkbox"/>	Definitely no	<input type="checkbox"/>	Probably no	<input type="checkbox"/>	Probably yes	<input type="checkbox"/>	Definitely yes														
<input type="checkbox"/>	Definitely no																						
<input type="checkbox"/>	Probably no																						
<input type="checkbox"/>	Probably yes																						
<input type="checkbox"/>	Definitely yes																						
<p>3. Which services of this facility need <u>improvement</u>?</p>	<p>_____</p> <p>_____</p> <p>_____</p> <p>_____</p> <p>_____</p>																						
<p>4. Are there any <u>issues</u> around good quality of TB care that you would like to mention and that were not addressed in this survey so far?</p>	<p>_____</p> <p>_____</p> <p>_____</p> <p>_____</p> <p>_____</p>																						

THANK YOU

Time interview ends
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SECTION D : INTERVIEW SETTING

Interviewer: please finish this interview by completing the last part of this questionnaire with details on the interview setting and the interview.

1. Facility

Health facility name	
District	
TB Zone	

2. Level of facility (country specific)

- Central hospital
- Hospital
- Health centre
- Dispensary

3. Type of facility (country specific)

- Government
- Private for profit
- Private not for profit
- NGO/ Missionary

4. Locality of facility

- Rural
- Urban

5. The interview:

Time taken for the whole interview:	

Your opinion about the interview:	
-----------------------------------	--

Annex C. QUOTE-TB Importance

QUOTE-TB/importance

Code number: / / /

QUOTE-TB

PART 2 IMPORTANCE

**PATIENT INTERVIEW
&
INSTRUCTIONS**

The QUOTE-TB questionnaire is being developed by the Regional Centre for Quality of Health Care (RCQHC) and National TB Programmes (NTPs) of Uganda, Kenya, and Malawi, with technical support from Royal Tropical Institute (KIT), KNCV Tuberculosis Foundation and the Netherlands Institute for Health Services Research (NIVEL) and financial support from USAID/REDSO and DGIS.

Instructions to the interviewer

When a patient has finished his/her consultation with the clinic staff, ask him/her if he/she is aware of being a TB patient, and willing to answer questions about the quality of TB services he/she has received. The interview will take approximately 30–40 minutes. It is essential that you gain his/her informed consent before beginning the interview, so the following introduction should be given.

Greet the patient

"Hello. My name is

I am interested in what you think about the services provided at this health facility. Your views and opinions are very important to further improve TB services. I would like to ask you questions about your visits to this health facility and the health providers that work in this facility. I would be very grateful if you could spend some time talking with me. I will not write down your name, and everything you tell me will be kept strictly confidential. Your participation is voluntary and you are not obliged to answer any questions you do not want to. Participating in this interview will not negatively affect the subsequent services you will get. Do I have your permission to continue?"

If no > stop the interview, thank the patient, note 'one refusal' on the non-respondent form, wait for another patient

If yes > continue with the interview. Note: only interview adult patients at least 2 weeks on treatment.

Tick this box whether the patient is a defaulter or not ¹ Yes ² No

Name Interviewer	
Date of interview	
Time interview starts	
Interview conducted in:	Specify language.
Interview conducted at:	Clinic: ¹ <input type="checkbox"/> Yes ² <input type="checkbox"/> No Community, specify where:.....

SECTION A: SOCIO-DEMOGRAPHIC CHARACTERISTICS AND GENERAL QUESTIONS

1. **Patient's sex** ¹ Male ² Female
2. **Patient's age** years
3. **What is your highest level of education?**
- ¹ None
- ² Primary (Standard 1-5)
- ³ Primary (Standard 6-8)
- ⁴ Secondary
- ⁵ Tertiary
- ⁶ Other:
4. **What is the main source of your livelihood?**
-
5. **Before you were diagnosed, what did you do first to get rid of your illness?**
- ¹ None
- ² Self medication
- ³ Traditional healers
- ⁴ Herbal medicine/therapy
- ⁵ Other, specify:
- ⁶ More than one action
6. **When did your symptoms start? (write response in dotted space below)**
-
7. **After what period did you first go to a health facility**
(probe the time lapse between the onset of symptoms and the first time patient went to a health provider/health facility)? (write response in dotted space and also check the corresponding option below)
-
- ¹ Within one (1) week
- ² Between one (1) and four (4) weeks
- ³ Between four (4) and eight (8) weeks
- ⁴ More than eight (8) weeks
8. **When were you diagnosed with TB for this illness?**
(write response in dotted space and also check the corresponding option below)
-
- ¹ Within three (3) weeks after the onset of symptoms
- ² Three (3) to eight (8) weeks after the onset of symptoms
- ³ More than eight (8) weeks after the onset of symptoms
9. **After diagnosis, when did you start TB treatment?**
- ¹ Within two (2) days
- ² Within one (1) week
- ³ More than one (1) week
10. **What was/were the reason(s) for your visit today? (Multiple answers possible)**
- ¹ Diagnosis, specify:
- ² Drug collection, specify:
- ³ Information/advice, specify:
- ⁴ Follow up sputum examination
- ⁵ Other, specify:

SECTION B: IMPORTANCE OF TB QUALITY ASPECTS; RATING

This part of the survey is about the quality of TB care and what you think is important in TB care. First, we would like you to rate a series of statements on a scale between 1 ('not important') to 4 ('extremely important'). We would like you to indicate after every statement how important you think it is. There are no right or wrong answers. The answering categories you can use are:

- 1 = not important
- 2 = important
- 3 = extremely important

B-1 : AVAILABILITY OF TB SERVICES

First, I would like you to rate nine aspects that have to do with the availability of TB services.

1. Waiting times before being served by providers during your visits should be within <u>acceptable range</u>	¹ <input type="checkbox"/> not important ² <input type="checkbox"/> important ³ <input type="checkbox"/> extremely important
2. At the TB facility you should have the <u>same health care providers</u>	¹ <input type="checkbox"/> not important ² <input type="checkbox"/> important ³ <input type="checkbox"/> extremely important
3. <u>Service hours</u> of the facility should be <u>convenient</u> for you to get your TB treatment	¹ <input type="checkbox"/> not important ² <input type="checkbox"/> important ³ <input type="checkbox"/> extremely important
4. TB drugs should be <u>available on the day you visit</u> the TB facility	¹ <input type="checkbox"/> not important ² <input type="checkbox"/> important ³ <input type="checkbox"/> extremely important
5. You should <u>not experience difficulties</u> in obtaining TB services because of language barriers	¹ <input type="checkbox"/> not important ² <input type="checkbox"/> important ³ <input type="checkbox"/> extremely important
6. You should <u>not go to different units</u> for TB services and treatment	¹ <input type="checkbox"/> not important ² <input type="checkbox"/> important ³ <input type="checkbox"/> extremely important
7. The TB facility should be <u>easy to reach</u>	¹ <input type="checkbox"/> not important ² <input type="checkbox"/> important ³ <input type="checkbox"/> extremely important
8. TB services should be <u>available during the opening hours</u> of the facility	¹ <input type="checkbox"/> not important ² <input type="checkbox"/> important ³ <input type="checkbox"/> extremely important
9. Health care <u>providers</u> you visit in the TB facility should be <u>available</u>	¹ <input type="checkbox"/> not important ² <input type="checkbox"/> important ³ <input type="checkbox"/> extremely important

B-2 : INFORMATION

Next, I would like you to rate seven items that have to do with information about TB and its treatment.

1. TB care providers should tell you when the <u>infectiousness</u> of TB stops	¹ <input type="checkbox"/> not important ² <input type="checkbox"/> important ³ <input type="checkbox"/> extremely important
2. TB care providers should tell you about the <u>curability</u> of TB	¹ <input type="checkbox"/> not important ² <input type="checkbox"/> important ³ <input type="checkbox"/> extremely important
3. TB care providers should tell you about the importance of <u>supervised intake of TB drugs (DOT)</u>	¹ <input type="checkbox"/> not important ² <input type="checkbox"/> important ³ <input type="checkbox"/> extremely important

4. TB care providers should tell you about the <u>side effects</u> of TB drugs	¹ <input type="checkbox"/> not important ² <input type="checkbox"/> important ³ <input type="checkbox"/> extremely important
5. TB care providers should tell you that you need <u>regular sputum tests</u> during your treatment (if applicable)	¹ <input type="checkbox"/> not important ² <input type="checkbox"/> important ³ <input type="checkbox"/> extremely important
6. TB care providers should tell you about the <u>duration</u> of the TB treatment	¹ <input type="checkbox"/> not important ² <input type="checkbox"/> important ³ <input type="checkbox"/> extremely important
7. TB care providers should tell you about how you can <u>store drugs</u> obtained for your treatment	¹ <input type="checkbox"/> not important ² <input type="checkbox"/> important ³ <input type="checkbox"/> extremely important

B-3 : PATIENT – PROVIDER INTERACTION AND COUNSELLING

Next, I would like you to rate eight aspects that have to do with the interaction between TB patients and health care providers.

1. TB care providers should treat you with <u>respect</u>	¹ <input type="checkbox"/> not important ² <input type="checkbox"/> important ³ <input type="checkbox"/> extremely important
2. TB care providers should <u>listen carefully</u> to you	¹ <input type="checkbox"/> not important ² <input type="checkbox"/> important ³ <input type="checkbox"/> extremely important
3. TB care providers should <u>explain things</u> in a way you can understand	¹ <input type="checkbox"/> not important ² <input type="checkbox"/> important ³ <input type="checkbox"/> extremely important
4. At the facility you should have <u>sufficient time</u> to discuss your problems	¹ <input type="checkbox"/> not important ² <input type="checkbox"/> important ³ <input type="checkbox"/> extremely important
5. At the facility health providers should discuss with you how to <u>deal with your problems</u> ?	¹ <input type="checkbox"/> not important ² <input type="checkbox"/> important ³ <input type="checkbox"/> extremely important
6. At the facility you should not experience <u>discrimination</u> because you have TB	¹ <input type="checkbox"/> not important ² <input type="checkbox"/> important ³ <input type="checkbox"/> extremely important
7. At the facility your <u>privacy</u> should be respected during consultations	¹ <input type="checkbox"/> not important ² <input type="checkbox"/> important ³ <input type="checkbox"/> extremely important
8. TB care providers should tell you how TB affects your <u>everyday life</u>	¹ <input type="checkbox"/> not important ² <input type="checkbox"/> important ³ <input type="checkbox"/> extremely important

B-4 : TB – HIV RELATIONSHIP

Next, I would like you to rate four aspects that have to do with the link between TB and HIV.

1. TB care providers should inform you about the <u>link between TB and HIV</u>	¹ <input type="checkbox"/> not important ² <input type="checkbox"/> important ³ <input type="checkbox"/> extremely important
2. TB care providers should inform you how to <u>prevent HIV</u> infection?	¹ <input type="checkbox"/> not important ² <input type="checkbox"/> important ³ <input type="checkbox"/> extremely important

3. After being diagnosed as a TB patient, you should be advised to be <u>tested on HIV</u>	¹ <input type="checkbox"/> not important ² <input type="checkbox"/> important ³ <input type="checkbox"/> extremely important
4. TB care providers should inform you where to get <u>HIV-treatment</u> in case you might need this	¹ <input type="checkbox"/> not important ² <input type="checkbox"/> important ³ <input type="checkbox"/> extremely important

B-5 : INFRASTRUCTURE

Next, I would like you to rate four aspects that have to do with the infrastructure of the TB facility you are visiting.

1. This TB facility should be <u>clean</u>	¹ <input type="checkbox"/> not important ² <input type="checkbox"/> important ³ <input type="checkbox"/> extremely important
2. There should be <u>safe drinking water</u> in this facility	¹ <input type="checkbox"/> not important ² <input type="checkbox"/> important ³ <input type="checkbox"/> extremely important
3. There should be <u>usable toilets</u> in this TB facility	¹ <input type="checkbox"/> not important ² <input type="checkbox"/> important ³ <input type="checkbox"/> extremely important
4. There should be <u>enough comfortable benches</u> in this TB facility to sit on	¹ <input type="checkbox"/> not important ² <input type="checkbox"/> important ³ <input type="checkbox"/> extremely important

B-6 : PROCEDURES AND TESTS

Next, I would like you to rate seven aspects that have to do with TB procedures and tests.

1. At the TB facility there should be <u>possibilities to have your sputum examined</u>	¹ <input type="checkbox"/> not important ² <input type="checkbox"/> important ³ <input type="checkbox"/> extremely important
2. You should have the possibility to <u>take my TB treatment at home</u>	¹ <input type="checkbox"/> not important ² <input type="checkbox"/> important ³ <input type="checkbox"/> extremely important
3. During your first visit to the TB facility, you should be <u>physically examined</u>	¹ <input type="checkbox"/> not important ² <input type="checkbox"/> important ³ <input type="checkbox"/> extremely important
4. To be diagnosed with TB, your <u>sputum</u> should be examined	¹ <input type="checkbox"/> not important ² <input type="checkbox"/> important ³ <input type="checkbox"/> extremely important
5. There should be not more than <u>2 working days</u> between your first sputum submission and the moment you were diagnosed with TB	¹ <input type="checkbox"/> not important ² <input type="checkbox"/> important ³ <input type="checkbox"/> extremely important
6. In case of germs in your sputum causing TB, your close <u>contacts should be examined</u> by the TB facility	¹ <input type="checkbox"/> not important ² <input type="checkbox"/> important ³ <input type="checkbox"/> extremely important
7. A treatment observer should <u>check on your daily intake</u> of TB drugs	¹ <input type="checkbox"/> not important ² <input type="checkbox"/> important ³ <input type="checkbox"/> extremely important

B-7 : COSTS AND PAYMENT

Next, I would like you to rate three aspects that have to do with the costs of TB services.

1. You should <u>not have to pay</u> for regular TB services (e.g. sputum tests, TB-drugs, etc)	¹ <input type="checkbox"/> not important ² <input type="checkbox"/> important ³ <input type="checkbox"/> extremely important
2. You should <u>not have to pay bribes</u> to get your TB treatment	¹ <input type="checkbox"/> not important ² <input type="checkbox"/> important ³ <input type="checkbox"/> extremely important
3. <u>Costs (e.g. transport) should not prevent</u> you from getting to your TB facility	¹ <input type="checkbox"/> not important ² <input type="checkbox"/> important ³ <input type="checkbox"/> extremely important

B-8 : SUPPORT

To conclude this rating exercise, I would like you to rate two aspects that have to do with the support received from the TB facility you are visiting.

1. You should receive support for <u>transportation</u> from the TB facility	¹ <input type="checkbox"/> not important ² <input type="checkbox"/> important ³ <input type="checkbox"/> extremely important
2. You should receive support for <u>food</u> from the TB facility	¹ <input type="checkbox"/> not important ² <input type="checkbox"/> important ³ <input type="checkbox"/> extremely important

SECTION B-2: IMPORTANCE OF TB QUALITY TOPICS; RANKING

Now, we would like to rank eight topics related to the quality of TB care according to their importance. The topic that you consider as being 'the most important' ends at the first place (place '1'); the second most important topic ends at place '2', etc. There are no right or wrong answers; we're interested in your personal views on these topics.

NB. SHOW ALL PICTURES TO THE PATIENT

I will mention to you eight general topics on good quality of TB care. What is for you the most important topic in terms of good quality of TB care? (NB Interviewer: this topic gets rank nr. 1).

And what is the second most important topic? (NB. Interviewer: this topic gets rank nr. 2).

And what is the third most important topic? (NB. Interviewer: this topic gets nr. 3). Etc..

(Interviewer: please note down the time the moment the respondent starts ranking)

Ranking start time _____

1. Availability of TB services	Rank ____
2. Information	Rank ____
3. Provider interaction and counselling	Rank ____
4. TB – HIV relationship	Rank ____
5. Infrastructure	Rank ____
6. Procedures and tests	Rank ____
7. Costs and payment	Rank ____
8. Support	Rank ____

Ranking end time _____

SECTION C: OVERALL RATING of THE FACILITY

Finally, we would like to know what you think about the quality of care that TB patients receive at this facility

<p>1. We would like to know your overall rating for this TB facility. Using any number from 0 to 10, where 0 is the worst and 10 is the best TB facility possible, what number would you use to rate this TB facility?</p>	<p><input type="checkbox"/> 0 Worst TB facility <input type="checkbox"/> 1 <input type="checkbox"/> 2 <input type="checkbox"/> 3 <input type="checkbox"/> 4 <input type="checkbox"/> 5 <input type="checkbox"/> 6 <input type="checkbox"/> 7 <input type="checkbox"/> 8 <input type="checkbox"/> 9 <input type="checkbox"/> 10 Best TB facility possible</p>
<p>2. Would you recommend this facility to your friends and family?</p>	<p><input type="checkbox"/> 1 Definitely no <input type="checkbox"/> 2 Probably no <input type="checkbox"/> 3 Probably yes <input type="checkbox"/> 4 Definitely yes</p>
<p>3. Which services of this facility need improvement?</p>	<p>_____ _____ _____ _____</p>
<p>4. Are there any issues around good quality of TB care that you would like to mention and that were not addressed in this survey so far?</p>	<p>_____ _____ _____ _____</p>

THANK YOU

Time interview ends
---------------------	-------

SECTION D : INTERVIEW SETTING

Interviewer: please finish this interview by completing the last part of this questionnaire with details on the interview setting and the interview.

1. Facility

Health facility name	
District	
TB Zone	

2. Level of facility (country specific)

- ¹ Central hospital
² Hospital
³ Health centre
⁴ Dispensary

3. Type of facility (country specific)

- ¹ Government
² Private for profit
³ Private not for profit
⁴ NGO/ Missionary

4. Locality of facility

- ¹ Rural
² Urban

5. The interview:

Time taken for the whole interview:	
Time taken for the ranking part (B-2):	

Your opinion about the interview:	
-----------------------------------	--

Annex D. Details of importance scores and ranking

Results of importance scores are presented below, including a breakdown by sex, urban/rural residence, and educational level. The labels of the quality aspects refer to the new version of QUOTE-TB. Importance scores refer to the percentage of the respondents in the 'extremely important' category.

Dimension 1: Availability

Quality aspect	% extremely important	Gender		Residence		Education	
		M	F	rural	urban	low	high
B1-1: Acceptable waiting times	47	46	47	42	52	45	49
B1-2: Same health provider	47	41	53	42	53	46	49
B1-3: Convenient service hours	63	56	59	55	60	61	52
B1-4: TB drugs available	78	79	77	74	82	78	78
B1-5: Difficulty because of language barrier	63	63	63	61	65	65	60
B1-6: To other health facility (without referral)	50	49	51	41	59	50	50
B1-7: Easy to reach (distance)	67	70	70	69	71	74	63
B1-8: TB services available during working hours	68	68	68	69	67	72	63
B1-9: Relevant provider available in facility	65	64	66	60	70	64	66

Dimension 2: Information

Quality aspect	% extremely important	Gender		Residence		Education	
		M	F	rural	urban	low	high
B2-1: Stop spreading TB to others	62	61	62	59	64	64	59
B2-2: TB can be cured	64	62	67	60	69	68	59
B2-3: Importance observed treatment	68	66	69	67	69	71	64
B2-4: Side effects of TB drugs	65	65	65	59	72	65	65
B2-5: Sputum tests at given times	67	65	68	59	74	70	61
B2-6: Duration of treatment	68	66	70	65	71	71	63
B2-7: Storage of TB drugs	64	59	68	63	64	68	57

Dimension 3: Provider interaction and counselling

Quality aspect	% extremely important	Gender		Residence		Education	
		M	F	rural	urban	low	high
B3-1: Treated with respect	69	69	70	68	70	70	68
B3-2: Listened to carefully	66	68	64	63	69	66	65
B3-3: Explained things in an understandable way	69	71	68	63	75	70	68
B3-4: Sufficient time to discuss problems	61	59	62	59	63	63	57
B3-5: Discussed how to deal with problems	---	---	---	---	---	---	---
B3-6: Discrimination because of TB	67	67	68	67	68	69	65
B3-7: Privacy respected	72	70	73	70	74	74	68
B3-8: Told how TB affects everyday life	71	70	72	65	77	72	70

Dimension 4: TB-HIV Relationship

Quality aspect	% extremely important	Gender		Residence		Education	
		M	F	rural	urban	low	high
B4-1: Informed about link between TB and HIV	70	73	68	62	79	67	75
B4-2: Informed how to prevent HIV infection	71	73	70	64	78	70	73
B4-3: Advised to take HIV test	76	79	74	69	83	77	76
B4-4: Informed where to get HIV treatment	78	79	76	76	79	81	73

Dimension 5: Infrastructure

Quality aspect	% extremely important	Gender		Residence		Education	
		M	F	rural	urban	low	high
B5-1: Facility clean	72	76	68	69	75	69	76
B5-2: Safe drinking water	68	65	72	66	71	67	70
B5-3: Usable toilets	74	74	73	69	78	73	74
B5-4: Comfortable benches	63	64	63	60	67	63	64

Dimension 6: Procedures and tests

Quality aspect	% extremely important	Gender		Residence		Education	
		M	F	rural	urban	low	high
B6-1: Sputum examinations	68	67	70	66	71	74	60
B6-2: Home-based TB treatment	53	51	56	56	50	54	52
B6-3: Physically examined	72	69	74	67	77	68	78
B6-4: Sputum examined	68	66	71	64	73	72	62
B6-5: Days between sputum submission and results	56	56	57	46	67	58	54
B6-6: Contacts examined	65	64	65	60	69	65	65
B6-7: Treatment observer for daily intake of drugs	57	54	59	58	56	62	48

Dimension 7: Costs and Payment

Quality aspect	% extremely important	Gender		Residence		Education	
		M	F	rural	urban	low	high
B7-1: Pay for regular TB services	---	---	---	---	---	---	---
B7-2: Pay a tip	82	85	79	76	87	78	87
B7-3: Costs prevent going to facility	69	70	68	59	79	68	71

Dimension 8: Support

Quality aspect	% extremely important	Gender		Residence		Education	
		M	F	rural	urban	low	high
B8-1: Transport	47	47	48	53	41	52	40
B8-2: Food	52	51	53	55	49	57	45

Annex E. Training instructions

ROLE OF THE INTERVIEWER

The interviewer occupies a central position in this survey, since he/she is the one who collects the information from the respondents. Therefore, the success of the survey depends on the quality of **each** interviewer's work. In general, the responsibilities of a household interviewer for the survey will include:

- Identifying the right respondent in the selected study sites/clinics. There are two selection questions as follows:
 - A.** Have you been on treatment for TB for at least three weeks?
1=Yes 2=No 3=I don't remember
 - B.** If yes, I would like to talk to you for a few moments. Is that fine?
1=Yes 2=No
- Identifying eligible respondents (in this particular study, TB patients in the study sites/clinics or home who have been on anti-TB drugs for at least three weeks).
- Guiding the patient to do the ranking of the nine dimensions of quality of health care and fill in the individual PIA/QUOTE-TB questionnaire.
- Checking completed questionnaires and interviews to be sure that all questions/quality of care statements were asked/responded to and the responses neatly and legibly recorded.

These tasks will be reviewed and discussed in detail from time to time throughout the training period. Before each training session, interviewers are advised to revise these tasks alongside the draft QUOTE-TB tool or questionnaire, writing down any questions they may have. Interviewers should ask questions they might have at any time, to avoid mistakes during actual interviews. They can learn a lot from each other by asking questions and talking about situations encountered in practice and actual interview situations.

THE ROLE OF TEAM LEADERS/SUPERVISORS

It is important to note that training is a continuous process. Supervision and guidance throughout the fieldwork programme are part of the training and data collection process. The team leaders or supervisors will play very important roles in continuing with training and ensuring the quality of the PIA/QUOTE-TB data. They will:

- Observe some of the interviews to make sure that interviewers/research assistants conduct themselves very well, asking the questions in the right manner and recording the answers correctly.
- Uncover apparent omissions and errors and take the necessary action.

- Review each completed QUOTE-TB questionnaire to be sure that it is complete and take the necessary action.
- Meet with each member of the team on a daily basis to discuss performance and give advice accordingly.
- Help interviewers to solve any problems that they might have in finding the right respondents, understanding the concepts in both parts of the QUOTE-TB questionnaire or with difficult respondents.
- Advise on technical issues especially in view of the fact that all the team leaders/supervisors are from a medical background while the research assistants are social scientists.

Note:

Team leaders are part and parcel of the data collection process. They are not any superior but rather fellow team players with whom high-quality data will be collected. They will help the team to ensure that instructions are followed.

ROLE OF THE FIELD GUIDE

In areas where CB-DOTS is in place, each research assistant will be assisted by a field guide (preferably two male and two female). We hope to use Local Council Executive officials, TB Focal Persons and/or community health workers that serve in the respective study sites and will guide the researcher to the different households to identify the TB patient, **but** they must not interfere with the patient's consent process. When a TB patient has been identified, the guide should wait nearby but not too near to compromise the respondent's privacy (either audio or visual).

CONDUCTING AN INTERVIEW

Each interview should start with informed consent of the respondent. An example of such an informed consent form is presented below..

Successful interviewing is an art and should not be treated as a mechanical process. Each interview is a new source of information, so we should make it interesting and pleasant. The art of interviewing develops with practice, **BUT** there are certain principles, which are followed by every successful interviewer. These may include but are not limited to:

1. Building a rapport with the respondent
2. Handling difficult or hard-to-interview respondents
3. Language of the interview
4. Field procedures, especially field editing of the completed QUOTE-TB questionnaires.

BUILDING RAPPORT WITH THE RESPONDENT

The interviewer and the respondent are strangers to each other, and one of the main tasks of an interviewer is to establish rapport. The respondent's first impression of the interviewer will influence his or her willingness to continue and cooperate with the study. **Be sure that your appearance is neat and your manner friendly** as you introduce yourself. Before you start work, introduce yourself to the respondents and explain why you are doing the study (see consent form).

CONSENT FORMS

No patient will be interviewed before consenting. A consent form has been translated into all the languages. Please make sure that each respondent signs and/or places their thumb print on two copies of the consent form. One copy has to be kept by the respondent, after the interviewer or witness has endorsed it. Explain clearly the essence of the copy the respondent will take home.

THINGS TO NOTE:

1. Make a good first impression

When first approaching the respondent, do your best to make him/her feel at ease. With a few well-chosen words you can put the respondent in the right frame of mind for the interview. Open the interview with a smile and salutation.

2. Always have a positive approach

Never adopt an apologetic manner, and do not use words such as 'Are you too busy?', 'Would you spare a few minutes?' or 'Would you mind answering some questions?' Such questions would invite refusal before you start the interview. Rather, tell the respondent, 'I would like to ask you a few questions' or 'I would like to talk to you for a few moments.' (Also see the Consent Form).

3. Stress confidentiality

(See the consent form.) If the respondent is hesitant about responding to the interview or asks what PIA/QUOTE-TB or the data will be used for, explain that the information will remain confidential, no individual names will be used for ANY purpose and that all information will be pooled to finalize PIA/QUOTE-TB. You should never mention other interviews or show completed questionnaires to other patients, interviewers or supervisors in front of a respondent or any other person.

4. Answer any questions from the respondent candidly

Before agreeing to be interviewed, the respondent may ask you some questions about the study or how he/she was selected to be interviewed. Be direct and pleasant when you answer.

The respondent may be concerned about the length of the interview. Inform the respondent that the duration of the performance interview will take between 10 and 20 minutes. The importance questionnaire with the ranking procedure can take up to 30 minutes.

5. Interview the respondent alone

The presence of a third person during the interview can prevent you from getting candid and honest answers from a respondent. It is therefore very important that the individual interview be conducted privately and that all questions are answered by the respondent alone. Interviews conducted outside the house, for instance under a tree, are preferable, as there is less chance they will be overheard.

CONSENT FORM FOR RESPONDENT TB PATIENTS

Introduction and objectives of the study

My name is..... I am conducting research to find out our people’s perceptions on the quality of care offered in health facilities. The information will be used by the government to plan and improve these services. Your participation is very important, as we seek to get your views.

Your part in the research and permission for writing/recording responses

We are seeking to get your views about the services you get from the TB clinic. If you agree to take part in the study, we will ask you to answer some questions. In order to report your views correctly, we would request you to grant us permission to record the interview, by ticking your option on each of the pre-set questions (in a questionnaire).

Confidentiality

The information that you will give us will be kept strictly confidential, and only the researchers are allowed to read the information. I will not write your name anywhere. Your answers will be anonymous, and at no time will a link be made between the answers given and the names of people who were interviewed.

Possible risks and benefits

You may not feel comfortable answering some questions in front of the interviewer. You have the right to refuse to answer any question or stop the interview at any time. Your refusal will not prejudice you or affect how you will be treated at your clinic or any other health facility. This study will not immediately or directly benefit the interviewees. However, it might benefit them in future when the government uses the information generated using the developed tool to plan and improve the quality of anti-TB services.

Consent

Participation in this study is voluntary. You are at liberty to refuse to answer any question or stop the interview at any time. Your refusal will not prejudice you or affect how you will be treated in this facility. The interview will last a maximum of about one hour.

When we have finalized our study, we would like to share the results with you, and you will receive an invitation for a discussion about the research at a later stage.

If you have any questions before the interview starts, we are happy to answer them.

Contact for questions

If you have any questions, now or in the future, about this study, please contact the principal researchers listed below. If you agree to participate after having received the above information, please sign: Agree to participate with note taking. Thank you,

Please put your signature here

Signature (Thumb print)

Witness

INTERVIEWING TECHNIQUES

a. Be neutral throughout the interview

Most people are polite and will tend to give answers that they think you would like to hear ('courtesy bias'). It is therefore important that you remain absolutely neutral as you make the statements or as you ask the questions. Never allow the respondent to think that he/she has given the 'right' or 'wrong' answer to the question – either by the expression on your face or by the tone of your voice. Never appear to approve or disapprove of any of the respondent's replies.

b. Never suggest answers to the respondent

If a respondent's answer is not relevant to a question, do not prompt him/her by saying something like 'I suppose you mean that Is that right?' In many cases, he/she will agree with your interpretation of his/her answer, even when that is not what he/she meant. Rather, you should probe in such a manner that the respondent him/herself comes up with the relevant answer. While in other studies we usually instruct interviewers **never to read out the list of pre-coded answers to the respondent**, even if he/she has trouble in answering, in this questionnaire it is not necessarily the case. Note that in the Importance part of QUOTE-TB there are several sections where you have to read the statement and then **read out all options as part of the statement: [statement] 1 = not important, 2 = important, 3 = extremely important**

Similarly, in the Performance part where options are: 1 Never, 2 Sometimes, 3 Usually, 4 Always; so you **read out all options as part of the statement: [statement]... and then complete it with: 1 Never, 2 Sometimes, 3 Usually, 4 Always.**

c. Do not change the wording or sequence of the questions/statements

The wording of the questions/statements and their sequence in the questionnaire must be maintained. If the respondent has misunderstood the question, you should repeat the question slowly and clearly. If he/she does not understand, you may re-word the question, being careful **not** to alter the meaning of the original question.

d. Handle hesitant respondents carefully

There will be situations where the patient/respondent simply says, 'I don't know', gives an irrelevant answer, acts very bored or detached, contradicts something he/she has already said, or refuses to answer the question. In these cases you may try to re-interest them.

e. Do not form expectations

You must not form expectations as to the ability and knowledge of the respondent. Do not assume that those TB patients from poor or sub-urban households or those who are less educated or illiterate do not know what they want. On the other hand, remember that differences between you and the respondent can influence the interview. If respondents believe that you are different from them, they may be afraid and mistrustful. You should always behave and speak in such a way that they are put at ease.

f. Do not hurry the interview

Ask the questions and read out the statements slowly to ensure the respondent understands what he/she is being asked. Avoid checking your watch too frequently during the interview; only do it once in a while and strategically. After you have asked a question or read the statement, pause and give the respondent time to think. If the respondent feels hurried or is not allowed to formulate his/her own opinion, he/she may respond with 'I don't know' or give an inaccurate answer. If you feel the respondent is answering without thinking, just to speed up the interview, SAY to the respondent, 'There is no hurry. Your opinion is very important, so consider your answers carefully.'

g. Language of the interview

The questionnaires for this study were designed in English and translated into Luganda, Lugwere and Ateso languages. Therefore, the interviewers in Wakiso and Kampala are expected to conduct interviews in Luganda, while those in Pallisa District will interview patients in Lugwere and Ateso. The plasticized cards were also translated into the three languages. If an index TB patient does not speak the main local languages into which we translated the tools and could be willing to be interviewed in English, interviewers shall use English. Questionnaires and plasticized cards in English will also be provided.

PROCEDURES FOR COMPLETING THE QUESTIONNAIRE

To collect the information needed, the interviewer must understand how to ask each question, what information the question is trying to explore, and how to handle any problems that might arise during the interview. It is also very important to know how to correctly record the answers that the respondent gives and how to follow special instructions (**especially how to do the ranking**) in the Importance part of the questionnaire.

a. Asking questions and or reading out the statements

It is very important to ask each question OR read out the statement exactly as it is written in the questionnaire.

In addition, when asking a question or reading out the statement, speak slowly and clearly so that the respondent will have no difficulty in hearing or understanding it. At times you may need to repeat the question/statement to be sure that the respondent understands it. In such cases, do not paraphrase the question/statement but repeat it exactly the way it is written. If, after you have repeated the question/statement, the respondent doesn't understand it, you may have to restate the question. BUT be careful when you change the wording, that you do not alter its original meaning.

b. Recording the responses

In this study, there are three types of questions:

1. Questions with pre-coded responses
2. Open-ended questions; and
3. Multiple-response questions (more than one answer – only Question 10 in Section 1 in both parts of the questionnaire.)

c. Correcting mistakes

It is very important that you record all the answers neatly. For the pre-coded responses, be sure that you circle the code for the correct response carefully. For the few open-ended questions, the reply should be written legibly so that it can easily be read. If you make a mistake in entering a respondent's answer or he/she changes his/her reply, be sure that you erase the incorrect response and enter the right one. Remember that if there are two responses for a particular question/statement, it may not be possible later, when the data is being coded, to determine which is the correct response.

d. Checking completed questionnaires

After you have completed an interview, you must review the questionnaire by carefully checking the answer to each question. It is important that you have not omitted any sections. If necessary, you may correct your handwriting or clarify answers. You should review the questionnaire BEFORE you leave the place of the interview, so that if you need any clarification, the respondent may still be available.

Good luck

Annex F. Picture cards for ranking and instructions for using

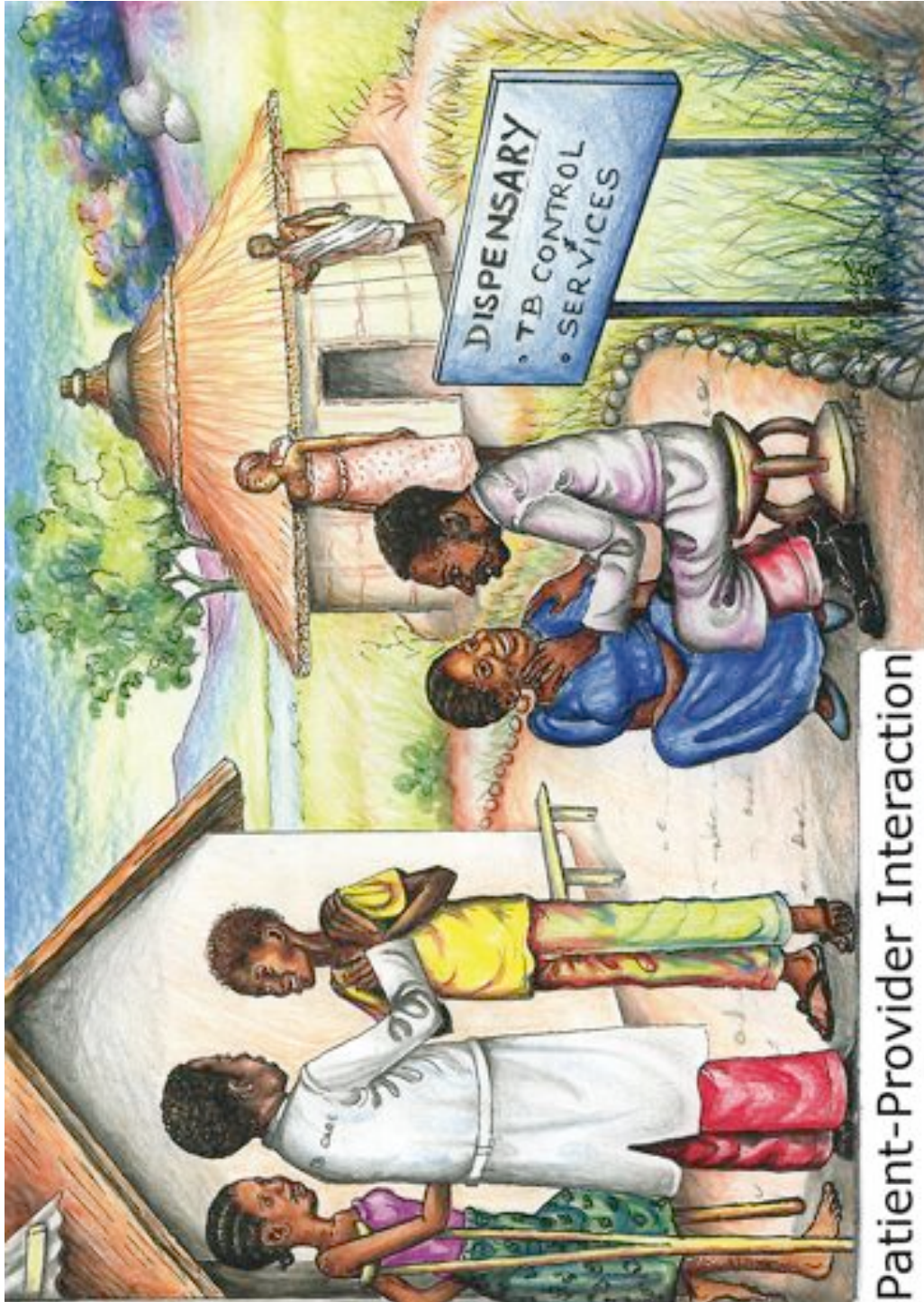
Instructions on how to use the laminated picture cards

Ensure that you preserve the laminated cards: It is possible that you may misplace some of the plasticized picture cards or even lose all of them. Should this happen, please use a photocopy of the cards, rather than using fewer cards or no cards at all. If no cards are used during the ranking exercise, please note this and ask the team leader to provide you with other cards.

How to effectively guide the respondent to do the ranking: With all respondents, whether or not they are literate, please use the LAMINATED CARDS throughout the ranking. The cards we are providing are supposed to have stickers labelled in English and in the local language. Before a respondent ranks the quality of care dimensions, please carefully explain each card before you lay it on a table or the floor (for easy visibility) to make the contents of each card clear. When a respondent picks a card, make sure you put it aside, i.e. the patient picks a card from the entire group of cards spread out on the floor or table and gives it to the interviewer, who then puts it aside.

The eight patient picture cards are presented on the following pages.

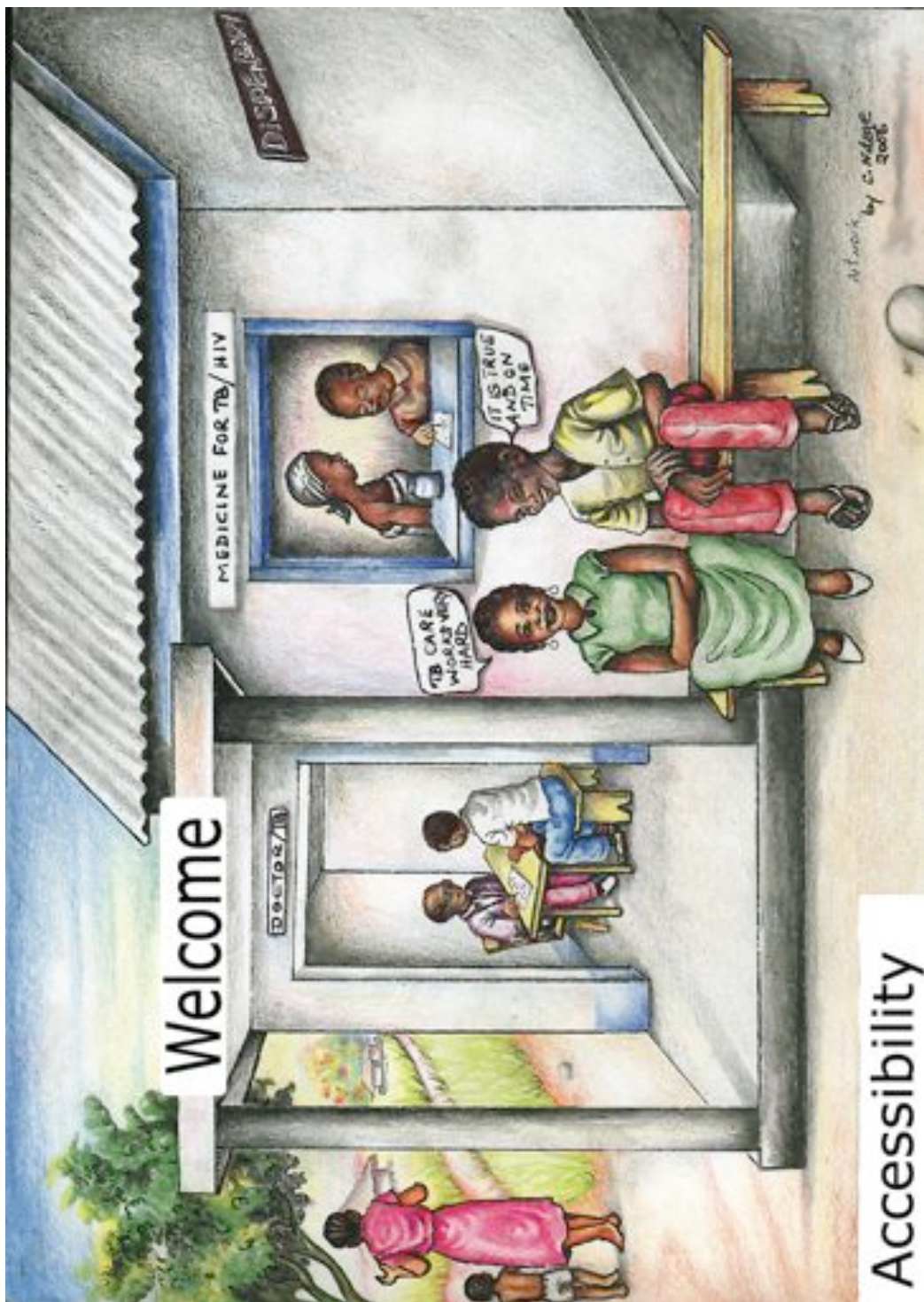
Note: these picture cards are examples only.



Patient-Provider Interaction



Information



Welcome

Doctor

Medicine for TB/HIV

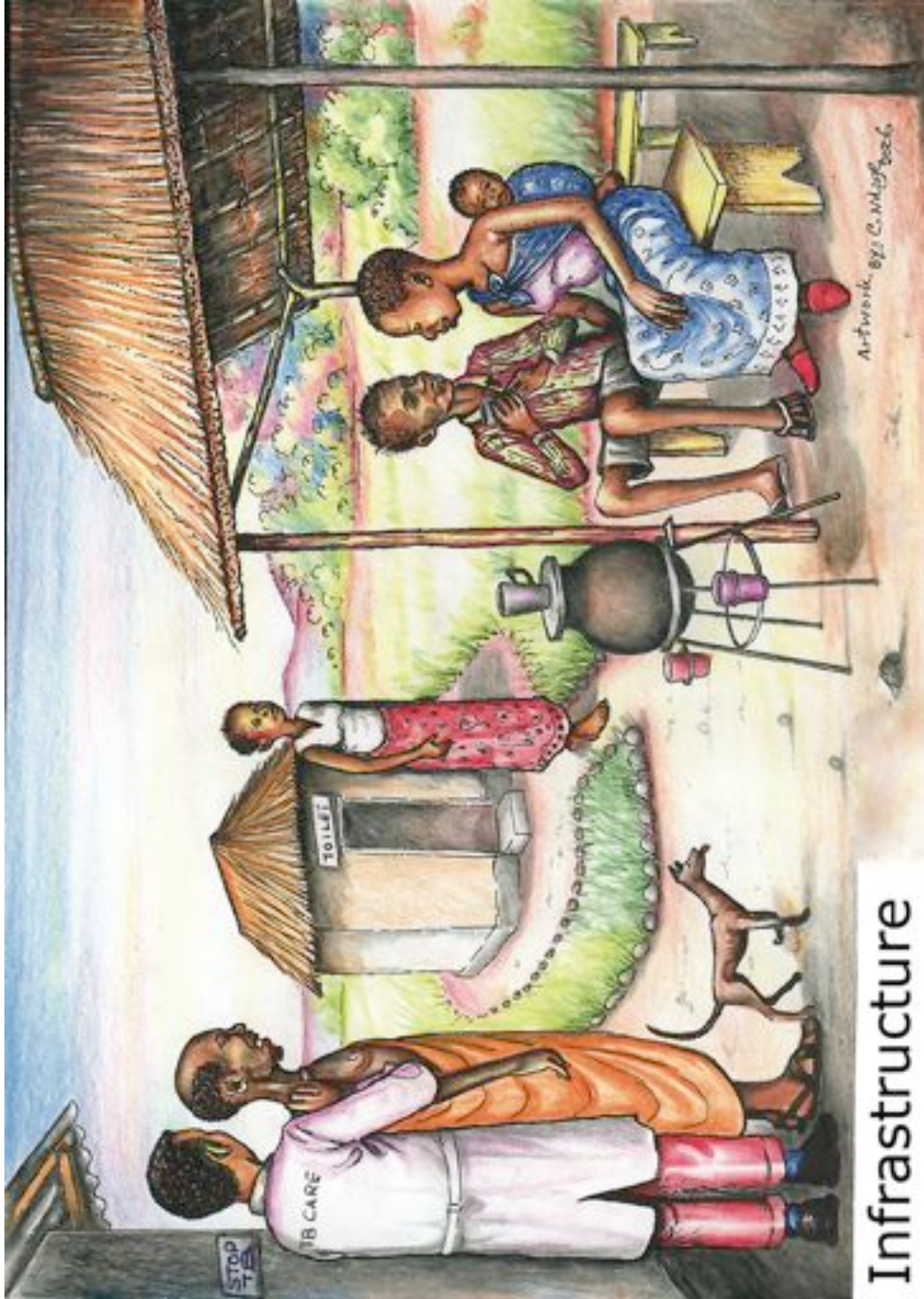
Dispensary

TB CARE WORKS VERY HARD

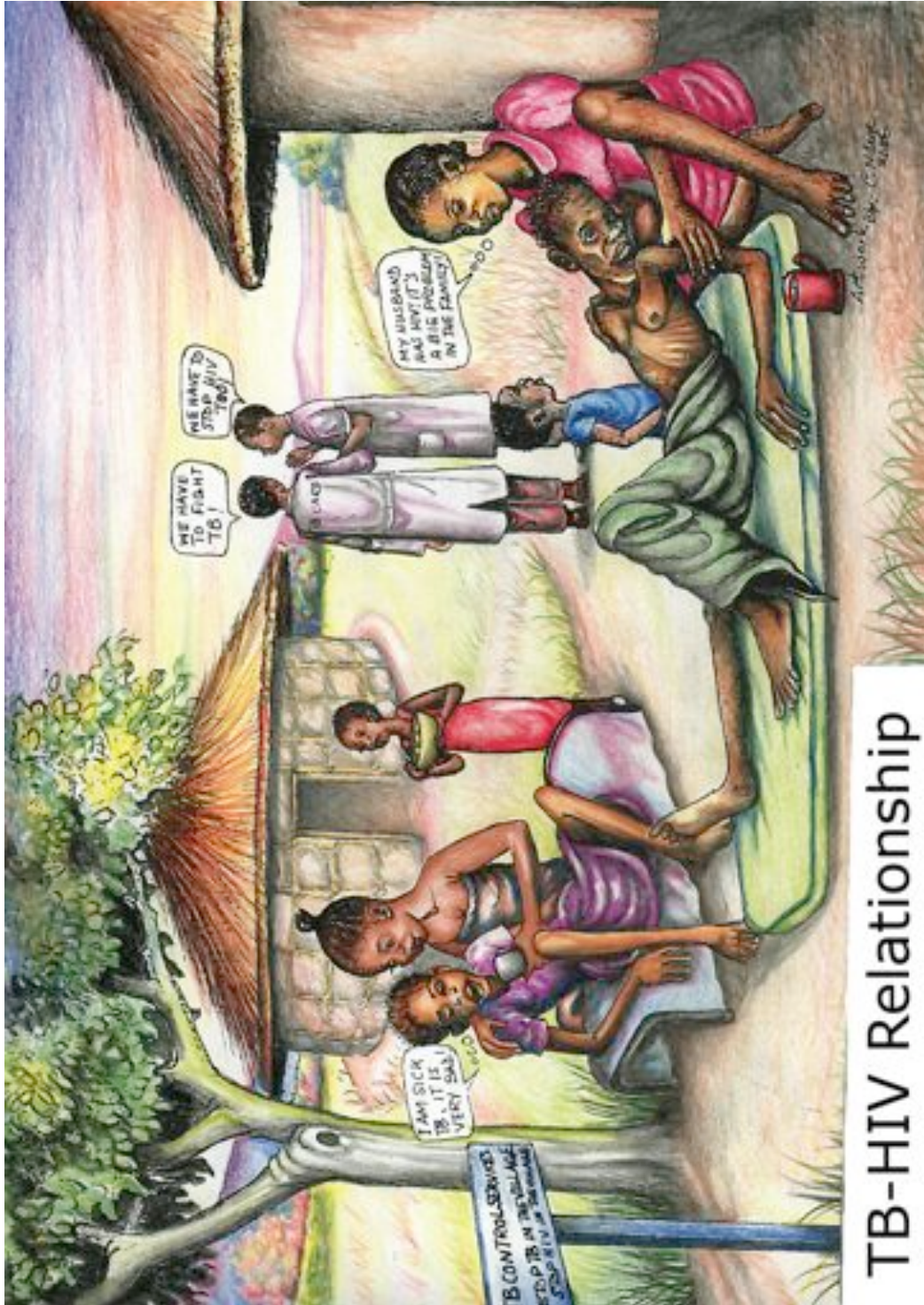
IT IS TRUE AND ON TIME

Accessibility





Infrastructure



TB-HIV Relationship

Annex G. Item characteristics, results of the item analyses and inter-item analyses

Results of importance scores in mean score and percentage of respondents in the 'extremely important' category of the quality aspects refer to the tested version of QUOTE-TB.

Item	Importance	
	Mean	% Extremely Important
B1 - Provider interaction and counselling		
1. During your visits to this facility, how often does the health provider treat you with <u>courtesy and respect</u> ?	3.68	69
2. During your visits to this facility, how often does the health provider <u>listen carefully to you</u> ?	3.63	66
3. During your visits to this facility, how often do health providers <u>explain things</u> in a way you can understand?	3.67	69
4. During your visits to this facility, how often do you have <u>sufficient time</u> to discuss your problems?	3.56	61
5. During your visits to this facility, how often do you have the possibility to discuss your <u>worries and concerns related to TB</u> ?	3.57	61
6. During your visits to this facility, how often do you experience <u>discrimination because you are a male/female</u> ?	3.41	60
7. During your visits to this facility, how often do you experience <u>discrimination because you have TB</u> ?	3.51	67
8. During your visits to this facility, how often is your <u>privacy respected</u> during examination?	3.68	72
9. Do health providers at this facility tell you how TB can <u>affect your every day life</u> ?	3.69	71
B2 – Information		
1. Do the health providers in this facility tell you when you <u>stop spreading TB to others</u> ?	3.58	62
2. Do the health providers in this facility tell you that <u>TB can be cured</u> ?	3.63	64
3. Do the health providers in this facility tell you about the importance of regular and <u>observed treatment</u> ?	3.55	68
4. Do the health providers in this facility tell you about the <u>side effects of TB drugs</u> ?	3.62	65
5. Do the health providers in this facility tell you about the need for <u>sputum tests</u> at given points during your treatment schedule?	3.61	67
6. Do the health providers in this facility tell you about the <u>duration of the TB treatment</u> ?	3.66	68
7. During your visits to this facility, do health providers tell you about how to <u>store your drugs obtained for your treatment</u> ?	3.56	64

Item characteristics, results of the item analyses and inter-item analyses
(cont.)

Item	Importance	
	Mean	% Extremely Important
B3 – Procedures and Competence		
1. How many times did you <u>go to health providers</u> with your health problems, before you were diagnosed with TB?	3.49	56
2. Were you <u>physically examined</u> during your first visit to this TB facility?	3.65	72
3. Was your <u>sputum examined</u> when you were diagnosed with TB?	3.65	68
4. How many (working) days were there <u>between</u> your first sputum submission and the time you got your results?	3.48	56
5. Was an X-ray made for the diagnosis of TB?	3.34	54
6. In case of germs in your sputum that cause TB, were your <u>close contacts examined</u> by the TB facility?	3.54	65
7. Are the <u>waiting time(s) before being served</u> by providers of this facility acceptable to you?	3.38	47
8. How often is there a <u>treatment observer checking</u> on your daily intake of TB drugs?	3.34	57
B4 – Availability of TB Services		
1. How often are <u>drugs available</u> when you require them?	3.77	78
2. Does this facility <u>examine your sputum</u> ?	3.65	69
3. Does the facility offer home based <u>TB treatment</u> ?	3.31	53
4. How often are you attended to by the <u>same health providers</u> in this facility?	3.05	47
5. How often do you have to go to <u>another health unit</u> for TB services or treatment?	3.09	50
6. Is your TB diagnostic facility <u>easy to reach</u> (distance)?	3.66	67
7. Is your TB treatment facility <u>easy to reach</u> (distance)?	3.69	72

Item characteristics, results of the item analyses and inter-item analyses
(cont.)

Item	Importance	
	Mean	% Extremely Important
B5 – Accessibility		
1. How often are <u>TB services not available</u> during the working hours of this facility?	3.67	68
2. How often do you experience <u>difficulties in obtaining TB services</u> in this facility because of language barriers?	3.46	63
3. How often are the <u>service hours</u> of this facility <u>convenient</u> for you to get your TB treatment?	3.48	57
4. How often are the relevant <u>providers</u> you come to see in this facility <u>not available</u> ?	3.54	65
B6 – Payment		
1. How often do you have to <u>pay for your TB drugs</u> ?	3.59	77
2. How often do you have to <u>pay to have your sputum</u> examined?	3.55	75
3. How often do you have to <u>pay for X-rays</u> (if applicable) taken for TB diagnosis?	3.48	70
4. How often do you have to <u>pay a tip</u> in order to get your TB services?	3.64	82
5. How often do <u>costs</u> prevent you from getting your TB services?	3.51	69
B7 – Infrastructure		
1. How often is this facility <u>clean</u> ?	3.71	72
2. How often is there <u>safe drinking water</u> in this facility?	3.64	68
3. How often are the <u>toilets</u> in this facility usable?	3.71	74
4. Are there enough <u>comfortable benches</u> to sit on in this facility?	3.52	63
B8 – Support		
1. How often do you receive transport <u>support</u> from the health facility?	3.1	47
2. How often do you receive <u>food support</u> from the health facility?	3.19	52
B9 – TB - HIV relationship		
1. Did health providers in the facility inform you about the <u>link between TB and HIV</u> ?	3.69	70
2. Were you informed by the health providers in this facility on how to <u>prevent HIV infection</u> ?	3.68	71
3. After being diagnosed as TB patient, were you advised to take an HIV test?	3.75	76
4. When tested HIV positive, can people in this facility get <u>treatment</u> for HIV infection?	3.75	78

Annex H. Results of the ranking procedure of quality dimensions

Results refer to the original nine cards that were ranked by the respondents. Presented are the mean scores, with '1' referring to the lowest ranking and '9' to the highest ranking. The scores refer to the tested version of QUOTE-TB.

Quality dimension	Residence		Education		Overall
	Rural.....Urban		Low	High	
Patient-provider interaction & counselling	5.4	5.5	5.4	5.4	5.4
Information	5.8	5.6	5.4	6.1	5.7
Professional competence & procedures	5.7	6.0	5.6	6.2	5.8
Availability	6.1	7.0	6.7	6.3	6.6
Accessibility	6.1	5.6	5.8	5.9	5.9
Payment	3.1	4.1	3.9	3.2	3.6
Infrastructure	4.4	4.0	4.1	4.3	4.2
TB-HIV relationship	4.3	4.4	4.2	4.6	4.4
Support	4.6	3.1	4.3	3.3	3.9

Quality dimension	Country			Overall
	Uganda	Kenya	Malawi	
Patient-provider interaction & counselling	5.6	5.0	6.8	5.4
Information	5.2	6.3	5.8	5.7
Professional competence & procedures	6.0	5.7	5.8	5.8
Availability	6.7	6.5	6.0	6.6
Accessibility	6.1	5.8	5.5	5.9
Payment	4.0	3.0	4.0	3.6
Infrastructure	3.9	4.4	5.0	4.2
TB-HIV relationship	3.9	4.8	4.8	4.4
Support	3.8	3.7	5.2	3.9

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