FALLING SHORT: A CIVIL SOCIETY PERSPECTIVE OF THE EUROPEAN RESPONSE TO MULTI & EXTENSIVELY DRUG RESISTANT TUBERCULOSIS (M/XDR-TB)

Annex 1

Abbreviations

ACSM	Advocacy, communication and social mobilization
CCM	Country Coordinating Mechanism
CSO	Civil society organization
DOTS	First component and pillar element of the Stop TB Strategy recommended for the control of tuberculosis
FSU	Former Soviet Union
HIV	Human immunodeficiency virus
HMDRC	High MDR-TB burden countries
HPC	High TB priority countries
IDU	Injecting drugs users
KAP	Knowledge, attitudes and practices
MDR-TB	Multidrug-resistant tuberculosis, resistant to isoniazid and rifampicin
M&E	Monitoring & Evaluation
MOH	Ministry of Health
NGO	Non-governmental organization
NTP	National Tuberculosis Programme
PHC	Primary health care
PWUD	People who use drugs
RCC-TB	Regional Collaborating Committee on Tuberculosis Control and Care
TB	Tuberculosis
USAID	United States Agency for International Development
WHO	World Health Organisation
XDR-TB	Extensively drug-resistant tuberculosis, resistant to isoniazid and rifampicin and to any one of the fluoroquinolone drugs and to at least one of the three injectable second-line drugs (amikacin, capreomycin or kanamycin)

Introduction

The consolidated action plan to prevent and combat M/XDR-TB 2011-2015 was launched by the WHO Regional Office for Europe and endorsed on 15 September 2011 by all 53 countries of the WHO European Region [1]. It was developed to strengthen and intensify the efforts to address the alarming problem of drug-resistant TB in the European Region [2] at the times when the total number of notified XDR-TB patients in the WHO European Region had almost tripled, from 132 in 2008 to 344 in 2009 [3, 4]. In 2012 in the European region from the estimated 76 400 MDR-TB cases, 33 373 (43.7%) had been detected [4]. In some countries of Eastern Europe and

Central Asia more than 20% of new TB cases and more than 50% of previously treated cases have MDR-TB [3]. A total of 339 XDR-TB cases were detected in the region, but the information about second line drugs susceptibility remains limited and it is estimated that 9.1% of MDR-TB cases have XDR-TB [4] or from the notified MDR-TB cases about 3 000 people.

By the end of 2015, the implementation of the consolidated action plan is expected to result in 225 000 MDR-TB patients being diagnosed, 127 000 drug-resistant TB patients treated successfully, 250 000 cases of MDR-TB and 13 000 XDR-TB cases averted and 120 000 lives saved. The economic gain in lives saved by the plan amounts to US$ 5 billion over the five years [2].

Today, with one and a half years left for the implementation of the plan, this report provides the members of TB Europe Coalition (TBEC) and the wider community with information about the achievements in the plan's implementation. At the beginning of 2014, TBEC with financial support of RESULTS UK has undertaken data collection and analysis, focusing on the indicators most relevant to civil society's participation in TB response and civil society organisations' (CSOs) collaboration with the government.

Out of the 67 indicators across seven intervention areas, eight indicators were chosen as the most relevant to the work of CSOs. Extent of the Plan's implementation, according to these eight indicators is presented in this report, followed by a few illustrative cases, recommendations and conclusions.

Methodology and selected indicators

Indicators' selection

Eight relevant outcome and output indicators from the consolidated action plan's Monitoring & Evaluation (M&E) framework [2] were selected based on their relevance to CSOs in terms of (1) forming partnerships inclusive of TB affected population/patients, (2) community systems strengthening strategies (or ACSM) based on evidence (KAP, satisfaction survey), (3) addressing the needs of the TB affected population and ensuring ethics and human rights, (4) availability of financial support from the government to CSOs in TB response.

The selected indicators are:

6.4.1. Regional multi-stakeholders coordination committee established and sustainably funded;

6.4.2. Number of Member States with a national Stop TB Partnership up and running with meaningful involvement of all stakeholders;

6.5.1. Number of Member States providing knowledge, attitudes and practice relevant to TB study/ies;

6.5.2. Number of Member States with a developed and fully funded national ACSM strategy and work plan;

6.5.3. Number of national Stop TB Partnerships, including patients' associations;

6.5.4. Number of Member States that financially support nongovernmental organizations active in TB control with specific emphasis on hard-to-reach populations;

6.6.1 Number of Member States with a patients' charter in place to ensure ethics and human rights;

6.6.3 Number of Member States having carried out client satisfaction assessments in the TB services.

Operationalization of indicators

To measure if partnerships are running and if the stakeholders' involvement is meaningfulness (indicator 6.4.2.) the respondents were asked to indicate the frequency of meetings and the most significant activities in 2012 organized by their partnerships, as well as partners who are not involved that should be involved.

Two indicators (6.5.2 and 6.5.4) mentioned above were operationalized differently from their original formulation. Indicator 6.5.2. "Number of Member States with a developed and fully funded national ACSM strategy and work plan" was expressed through five questions in the online questionnaire. First question inquired if there has been joint planning for ACSM and MDR-TB to understand if any efforts have been made to ensure that there was a planning process where ACSM strategies were developed or adjusted to address MDR-TB. Next four questions, to measure the same indicator 6.5.2 made a distinction between (1) having an ACSM strategy, (2) having the funding for the ACSM strategy, (3) having an ACSM work plan and (4) having the funding for the ACSM work plan. The reason is that from the experience of country reviews sometimes the first step - ACSM strategy development - is made, but eventually the strategy remains not (fully) funded or translated into work plans. It was important to distinguish what countries of the region had made what steps.

With regards to indicator 6.5.4 "Number of Member States that financially support nongovernmental organizations active in TB control with specific emphasis on hard-to-reach populations" two questions were added to substantiate the responses regarding: (1) the number of such CSOs supported and (2) an approximate total amount of such support, going from the government to the CSOs.

A question was added to the indicator 6.6.3 "Number of Member States having carried out client satisfaction assessments in the TB services" to determine if CSOs were involved in these assessments.

The remaining indicators were put in form of questions without further elaborating or breaking them down into sub-questions. For instance indicator 6.6.1 "Number of Member States with a patients' charter in place to ensure ethics and human rights" remained as it was in the consolidated action plan's M&E framework and did not specify if it was about an international patients' charter [7] or a national patients' charter.

Additional questions and information

In addition to the questions that were directly related to the indicators of the M&E framework, the respondents were asked to indicate: (1) if in the past three years the relationship between the government and the CSOs improved and how, and (2) to provide other comments.

The respondents

Only the answers from the respondents from the WHO European region were collected. The respondents were asked to provide contact information only in case they would be willing to be approached for clarification. The respondents were also asked to indicate which sector or group best described them:

Current or former TB patient
TB activist or volunteer
Staff member of a non-governmental organization (CSO)
Staff member of an international organization
Staff member of the National TB Program
Staff member of a governmental organization
Staff member of a donor organization
Freelance consultant

Level of analysis

The same level of analysis was used as in the consolidated action plan's M&E framework.

Data was collected for 18 High Priority Countries (HPC), and disaggregated for:

> (1) 18 HPCs - Armenia, Azerbaijan, Belarus, Bulgaria, Estonia, Georgia, Kazakhstan, Kyrgyzstan, Latvia, Lithuania, Republic of Moldova, Romania, Russian Federation, Tajikistan, Turkey, Turkmenistan, Ukraine, Uzbekistan - and
>
> (2) 15 high MDR-TB countries (HMDRC)[1] which are the same as the 18 HPC but excluding Romania, Turkey and Turkmenistan

Analysis did not cover all 53 member states, because of a lack of available secondary information and survey respondents from Europe, except Eastern Europe. This affected only one of the selected indicators for which the level of analysis included all 53 countries of the region: indicator 6.5.4 "Number of Member States that financially support nongovernmental organizations active in TB control with specific emphasis on hard-to-reach populations".

Data collection

The main means of data collection was a questionnaire circulated via TBEC listserve and through WHO country offices. The questionnaire was available for filling in online during one month. Additional qualitative information was collected by means of 12 group and individual face-to-face semi-structured interviews with CSOs. Information was requested and received by email from several questionnaire respondents who had indicated their willingness to provide clarification and details upon request. Besides CSOs, National TB Programs and WHO TB Country Technical Officers were approached to provide details in cases where information provided by several respondents from the same country was contradicting or otherwise inconclusive.

A request was sent to WHO office for Europe and all 11 WHO country offices located in high priority countries to provide a copy of the national MDR-TB Action Plan if available. The TB Country Technical Officers of WHO for European region were also asked to forward the online questionnaire link to civil society in their countries.

[1] selected on the basis of an estimated absolute number of at least 4000 MDR-TB cases arising annually and/or at least 10% of all newly registered TB cases estimated with MDR-TB, as of 2008.

The limitations of the data collection were (1) there was only one respondent per country for Bulgaria, Estonia, Turkey, Turkmenistan and Uzbekistan; (2) some information, especially if and how Patients' Charters are used to ensure ethics and human rights was not validated.

Interpretation of the responses

If the majority of the respondents from the same country answered "Yes" or "No" to a question then respectively in the annexed tables a "Yes" or "No" are recorded. If the answers were mainly "I do not know" and in cases where respondents answered "yes", "no" and/or "I do not know" to the same question in almost equal proportions, then the table record is "undetermined". All information ensuing from the questionnaire was compared with additional information collected from interviews and available documents (national MDR-TB plans, advocacy strategies, KAP survey results, program reviews). In some cases initially "Undetermined" statuses for the relevant indicator were changed to "Yes" or "No" depending on the additional supporting documentation and information.

Results

92 respondents from 18 HPCs answered the questionnaire, giving quantitative and qualitative information. The majority of the respondents were from CSOs (Table 1) and the numbers of respondents per country varied from 1 to 15 (Table 2).

Table 1. Composition of the respondents by sector/group

Sector/group represented	Number of respondents
Current or former TB patient	4
TB activist or volunteer	7
Staff member of a non-governmental organization (CSO)	47
Staff member of an international organization	10
Staff member of the National TB Program	11
Staff member of a governmental organization	3
Staff member of a donor organization	4
Freelance consultant	6
Total	**92**

Table 2. Number of respondents per country

#	Country	Number of respondents
1	Armenia	3
2	Azerbaijan	6
3	Belarus	5
4	Bulgaria	1
5	Estonia	1
6	Georgia	14
7	Kazakhstan	3
8	Kyrgyzstan	11
9	Latvia	4

10	Lithuania	3
11	Republic of Moldova	8
12	Romania	9
13	Russian Federation	3
14	Tajikistan	3
15	Turkey	1
16	Turkmenistan	1
17	Ukraine	15
18	Uzbekistan	1
	Total	**92**

A total of nine national MDR-TB Action Plan, some stand-alone and in a few cases integrated in overall Strategic National TB Plans were received from Armenia, Belarus, Kyrgyzstan, Romania, Tajikistan, Ukraine and Uzbekistan. WHO office in Azerbaijan informed that an MDR-TB action plan has been developed with their assistance and endorsed by the Ministry of Health (MOH) at the end of 2012. In Latvia MDR-TB response plan was developed and send to WHO, but it was not officially approved by the MOH, that decided that the plan should be considered as an adaptation of the current National TB program 2013 – 2015. In Estonia and the Republic of Moldova there were no standalone MDR-TB Action Plans, rather the MDR activities were integrated in the National Strategic Plans. In Georgia the National TB Strategy for 2013-2015 included specific objectives to address MDR-TB. From secondary sources (WHO website) it was identified that MDR-TB Action Plans were also available in Bulgaria and Kazakhstan. **The HPCs where information about the existence of such MDR-TB Action Plans was unavailable as of February 2014 were: Lithuania, Russian Federation, Turkey and Turkmenistan.**

Indicator 6.4.1. Regional multi-stakeholders coordination committee established and sustainably funded to assist in scaling up response to MDR-TB

Layer of analysis: WHO European Region

Source: Desk review

Progress until 2014: A regional multi-stakeholders coordination committee is established and is sustainably funded to assist in scaling up response to MDR-TB.

In 2013 WHO/Europe established the Regional Collaborating Committee on Tuberculosis Control and Care (RCC-TB). The mission of RCC-TB is to achieve universal access to evidence-based TB and M/XDR-TB prevention, diagnosis, treatment and care across the WHO European Region. The key objectives are to strengthen involvement and foster collaboration between national and international partners in TB and M/XDR-TB prevention, control and care.

Secretarial support of RCC-TB and funding of the running costs for e.g. yearly meetings, is covered by the WHO Regional Office for Europe. RCC-TB is a sustainable mechanism: it mainly works due to pro-bono time allocated by its members. WHO Regional Office for Europe is committed to support RCC-TB as long as TB is a public health priority in the European region.

Indicator 6.4.2. Number of Member States with a national Stop TB Partnership up and running with meaningful involvement of all stakeholders

Layer of analysis: 18 HPC (high priority countries) 15 HMDRC (high MDR priority countries).

Target: 18 HPC including 15 HMDRC

Progress until 2014: Republic of Moldova*, Romania, Tajikistan*, Turkey, Ukraine* – are the 5 of the HPCs (28% of the target), including 3 HMDRC marked with an asterisk (20% of the target) have a Stop TB Partnership or a similar structure.

Annex 1.1 gives detailed information about the HPCs that currently have a national Stop TB Partnership or a similar structure is established, comments on this structure's functioning, if all relevant stakeholders are represented in the structure and if not, what organizations or groups could be invited.

Following the example of the international Stop TB Partnership, a national Stop TB Partnership is expected to be a body uniting a wide range of constituencies. They give the partnership the credibility, access to medical, social and financial expertise and the power to align actors in the fight against TB. Whereas National TB Programs (NTPs) are in some cases registered as non-governmental entities and their staff have high levels of TB-related expertise, they neither include a broad range of stakeholders nor represent different constituencies. Country Coordinating Mechanism (CCM) on the other hand represent government, civil society and bilateral/multilateral partners, and have links with constituencies. However their primary objective, at least currently, is related to Global Fund grants and so their functions and mandate do not cover TB response that goes beyond the Global Fund financed activities. In the present report NTPs were not considered to be equal to a national Stop TB Partnership. The same applied to CCMs, unless the role of the stakeholders including CSOs, TB affected communities and (ex-)TB patients in a CCM was significant and explained as such by the respondents.

A structure that can grow out to become a national Stop TB Partnership is a TB Working Group, which is currently a part of the CCM in Azerbaijan. It is comprised of CSOs, including many CSOs working in TB, whose contribution to TB response is acknowledged at the country level. Hopefully by the time the Global Fund phases out, the TB Working Group can mature enough, establish and maintain strong links with their constituencies, and widely prove their added benefit so as to continue to exist, funded from the national budget. To form a strong national Stop TB Partnership it should include other stakeholders, primarily patients' organization(s) or TB activists, as well as government, bilateral organizations and others involved in combatting TB.

Only Turkey and Ukraine respondents indicated that all relevant stakeholders are present in their partnerships and there is no one missing. In the Republic of Moldova some of the respondents stated that all relevant stakeholders are part of the national Stop TB Partnership, while other respondents indicated that HIV service organizations, people who use drugs (PWUD) and injecting drugs users (IDU) are not currently represented and should be added to the Partnership. Most quoted other countries' examples of such missing partners included primarily TB patients and their organizations and other CSOs, followed by professional medical associations, parliamentarians and other relevant government institutions, CCM members and academia.

Indicator 6.5.1. Number of Member States providing knowledge, attitudes and practice relevant to TB study/ies

Layer of analysis: 18 HPC and 15 HMDRC

Target: 18 HPC including 15 HMDRC

Source: Routine reporting, WHO data available for 2010 - 2012

Progress until 2014: 13 of the HPC (77% of the target) – all <u>except</u> Estonia, Latvia, Lithuania, Turkmenistan and Uzbekistan - have conducted a KAP survey in the last 5 years. This includes 11 HMDRC (73% of the target).

A Knowledge, Attitudes, Practices (KAP) survey is a representative study of a specific population to collect information on what is known, believed and done in relation to a particular topic [5].

In Moldova a KAP survey among vulnerable groups – MSM, IDU, CSW – was conducted in 2012, CSOs were among the 10 stakeholders involved in the KAP. In Kyrgyzstan, 5 respondents indicated that a KAP survey was conducted and 6 that it was not conducted in the past 5 years. As a matter of fact, a KAP survey was conducted, funded by the USAID, among 5762 respondents in 2013 and 3248 respondents in 2014 to measure the people's knowledge regarding what is TB and how it is transmitted. In Belarus and Romania many respondents, including CSOs, did not know that a KAP was actually conducted in the recent past. In Latvia according the Department of Methodology and Supervision in TB and Lung Disease center there is no information about a KAP survey in the past last 5 years, although some respondents indicated that such a survey was carried out possibly referring to a survey about ambulatory care, conducted around year 2000, which was never officially published. In Armenia it was planned to conduct a KAP survey to inform ACSM activities in 2012. However, there were no funds for it. More detailed information regarding the availability of KAP surveys in the countries in the past 5 years is in Annex 1.2.

Well designed and carried out KAP surveys demand expertise and are relatively expensive. After carrying out a KAP survey its utility is in providing relevant stakeholders, including CSOs with valuable information necessary to adjust current or create new activities. In a country where the results of a KAP exist but do not, for any reason, reach the relevant stakeholders, as could be the case in Kyrgyzstan, Latvia and Romania, the benefits that could be derived from a KAP are limited. One of the tasks of a national Stop TB Partnership would be to promote sharing among the partners, such as KAP results, and making information easily (via a website, distribution lists, dissemination meetings and workshops) available to the interested parties.

Indicator 6.5.2. Number of Member States with a developed and fully funded national ACSM strategy and work plan

Layer of analysis: 18 HPC and 15 HMDRC

Target: 18 HPC including 15 HMDRC

Source: Desk review

Progress until 2014: none of the countries has a developed and fully funded national ACSM strategy and work plan

Development of ACSM strategies (done by Armenia, Azerbaijan, Belarus, Bulgaria, Georgia, Kazakhstan, Kyrgyzstan, Republic of Moldova, Tajikistan, Turkey, Ukraine and Uzbekistan) and plans (done by Azerbaijan, Belarus, Bulgaria, Georgia, Kazakhstan, Kyrgyzstan, Republic of Moldova, Tajikistan), even though they may not currently be funded, is an important step, as the documents can be used as advocacy tools in order to obtain funding. More detailed information is in Annex 1.3.

DR-TB management capacity including expanded advocacy, partnership building and policy developments of the National MDR Plan of Armenia include ACSM strategy development and plan. This area of interventions was budgeted with 527,961 Euros, however, to implement a comprehensive set of measures, additional funding of 269,522 Euros was needed. It was noted in the document that ACSM is the weakest sub-area among the interventions. ACSM strategy was planned to be developed in 2012, however the estimated budget for the development of the strategy was zero Euros.

Out of 6 respondents from Azerbaijan, representing CSOs, a donor, the NTP and a TB activist, only 4 were informed about the existence of the ACSM strategy, only 3 were aware about the (absence of) finances of the ACSM strategy and only 2 knew that there is an ACSM work plan. The work plan is not funded. The case of Azerbaijan shows how the knowledge about existing instruments diminishes, the closer one gets to the front line of their actual implementation.

In Georgia there is a "National Strategy for Advocacy, communication and social mobilization in Tuberculosis control, 2011-2013". Subsequently USAID Georgia Tuberculosis Prevention Project developed "Advocacy, Communication and Social Mobilization (ACSM) Strategy For USAID Georgia Tuberculosis Prevention Project 2012 – 2015", which outlines ACSM strategy and activities but only for this specific project, without a budget specification for its implementation.

In Kyrgyzstan there is an ACSM strategy, developed for 2013-16, operational ACSM plans are made every year. Many international organizations are involved in implementation of some ACSM activities, funded mainly by the Global Fund or the USAID. Activities are coordinated via a formal ACSM thematic working group and the informal advocacy or communication meetings. Since the strategy or the plan are not budgeted, no money from the government is contributed, the ACSM technical working group does not have any power or a mechanisms of central monitoring of ACSM activities implementation.

In Latvia, out of 4 respondents 2 were from CSOs, 1 from a governmental organization and 1 was a TB activist. The three out of four respondents agreed that there was a joint planning of ACSM activities for MDR-TB, however further information requests showed that the current national TB plan includes only some ACSM activities that target population in general and are not specifically tailored to address the MDR-TB challenge. Regarding the existence of ACSM strategy the opinions split: both CSOs indicated there are no ACSM strategy or work plan, the government employee reported that there are both an ACSM strategy and a plan but both are only partially funded. One of the respondents mentioned that “quite a lot of ACSM activities are implemented and funded by CSOs - for example, the ACSM section of the “TB prevention plan

2013-2015" includes implementation of "Empowering public health system and civil society to fight tuberculosis epidemic among vulnerable groups" (TUBIDU) project in Latvia (http://www.tai.ee/en/tubidu). This project is co-funded by the Executive Agency for Health and Consumers and the Health Program of the European Union. In Latvia, the project is lead and co-financed by a Latvian CSO "Tuberculosis Foundation of Latvia", no funding for this project comes directly from the Latvian government. The TB activist admitted not knowing if an ACSM strategy or work plan exist.

In 2008 in Romania "Developing a national strategy for advocacy, communication and social mobilization on TB" project was implemented, financed by the Global Fund. The resulting document contains a wealth of information, much of which can still be used for planning and decision-making. Even though the document is called "ACSM Strategy" it is rather general; it does give information and many options that should be considered while making a more specific ACSM strategy and plan. The document contains an assessment of the needs of TB patients that can be used in order to strengthen community systems and address existing problems of the TB patients. The document contains a KAP and a client satisfaction survey, both gave rich information including the extent of family and community support, stigma and discrimination. Finally the document gave recommendations regarding the activities to engage people with TB and communities including operational planning with strong M&E, promoting the Patients' Charter, increasing the involvement of private providers and strengthening the national TB Partnership.

Indicator 6.5.3. Number of national Stop TB Partnerships, including patients' associations

Layer of analysis: 18 HPC and 15 HMDRC

Target: 18 HPC including 15 HMDRC

Source: Desk review

Progress until 2014: - Republic of Moldova*, Romania, Tajikistan*, Turkey and Ukraine* - 5 of the HPC (28% of the target), including 3 HMDRC marked with an asterisk (20% of the target) include patients or patients organizations.

All five existing national Stop TB Partnerships (Republic of Moldova, Romania, Tajikistan, Turkey, Ukraine) include TB patients or TB patients' organization as a member of the partnership. More information is in Annex 1.4.

Indicator 6.5.4. Number of Member States that financially support nongovernmental organizations active in TB control with specific emphasis on hard-to-reach populations

Layer of analysis: 18 HPC and 15 HMDRC

Target: 18 HPC including 15 HMDRC

Source: Desk review

Progress until 2014: in 2 HMDRC – Bulgaria* and Kazakhstan* – the government

financially supports CSOs for TB, that is 11% among HPCs and 13% among HMDRC

Only the respondents from Bulgaria and Kazakhstan reported government's financial support to CSOs working in TB. More detailed information is in Annex 1.5.

The respondents from Armenia, Azerbaijan and Ukraine mentioned non-financial government support to patient advocates. Examples of such support are: in Armenia - "mostly through political commitment and acceptance of the importance of involving communities and CSOs in patient adherence issues. Also, some CSOs are involved in social support activities with the support of the Global Fund"; in Azerbaijan – "through discussion and sharing the information during meetings, round tables and trainings"; in Ukraine – "participation in the development of national programs and in the decision-making".

In Armenia the government recognizes the importance of involving communities and non-governmental organizations in patient adherence issues however the tools and guidance are needed on "how" to involve them. There are possibilities of social procurement in Azerbaijan, but no further details were available and out of 6 respondents from Azerbaijan only one indicated that there is assistance to treatment supporters from the state. In Belarus: social workers and psychologists salaries are supported by the state, however these specialists are part of the state structures. In Georgia only one out of 13 respondents replied that there is support from the government but did not provide details.

In Belarus social procurement by CSOs working in MDR-TB is considered. In Kyrgyzstan the Model of Social Procurement orders started to be implemented in the past through the Ministry of Social Protection, when five CSOs were funded with a total amount of €30,000 including one CSO providing TB/HIV services. The MOH can also use social procurement to outsource activities to CSOs, but does not do so currently. In Kazakhstan there are social procurement orders for CSO's. MOH was allocated 137 million Tenge (~€550,000.00) for CSO's in 2012, 93 million Tenge (~€373,000) in 2013, and has allocated 151 million Tenge (~€605,000) for 2014. This money could be used to advocate for patients rights. In addition, the government supports CSO initiatives to form treatment support groups and provided medical staff to attend treatment support groups to answer the patients' questions."

In the Russian Federation the responsibilities for DOT are regulated by the MOH decree are delegated to nurses of TB services and partially to the PHC. Salaries are being paid from the state and regional health budgets. In some regions, social workers are involved in incentive programs. No government support to CSOs working with vulnerable populations was mentioned.

In Tajikistan the government is piloting community-based or ambulatory TB treatment and support. In this model the primary health care staff are supported by the representatives of CSOs, civil society, community activists and religious leaders in TB prevention, diagnostic, treatment and support activities. One respondent mentioned that in Tajikistan there is an improvement in collaboration between the government and CSOs. There is a national strategy for health 2010-2020 – and a yearly national forum. At the latest forum in December 2013 the deputy Minister of Health mentioned that MOH wants to strengthen collaboration with the CSOs. This intention was translated in the national working plan, it is costed and there is a contribution of MOH and international partners.

From a mapping exercise, conducted in 2012 among 48 CSO from the HPC of the European region, it surfaced that 33% were involved in MDR-TB related activities and 66% in TB/HIV [6]. The most substantial donor was the Global Fund with 42% of CSOs fully or partially supported by its funds. For 40% of these CSOs the Global Fund was the only source of financing. National governments partially supported 23% and never fully supported any CSO, among the 48 organizations that participated in the mapping. For some countries the next Global Fund grant for TB may well be the last one.

Indicator 6.6.1 Number of Member States with a patients' charter in place to ensure ethics and human rights

Layer of analysis: 18 HPC and 15 HMDRC

Target: 18 HPC including 15 HMDRC

Source: routine reporting, WHO information available for 2011, 2012

Progress until 2014: Bulgaria and Estonia - 2 HMDRC have or use the Charter to safeguard human rights and ethics. That is 2 out of 18 HCP (11%) or 13% of the 15 HMDRC.

Bulgaria and Estonia have reported to use the Patients' Charter. Detailed information about this indicator is in Annex 1.6.

In Georgia, among 13 respondents 4 respondents said "no, it is not used", 2 "yes" and 2 (including one respondents from the national TB program) said "I don't know", the rest did not give an answer.

In Kazakhstan the issue of the Patients' Charter has been raised but the government felt that the patients' rights were covered for under the existing laws and would also be addressed under the Comprehensive Health Plan. Similar situation was reported in Azerbaijan, Belarus and Latvia. One respondent commented on the law "On combatting TB in Azerbaijan Republic" dated 02 May 2000 issued by the President which is still in use in Azerbaijan: "During the past 12 years the TB situation in the country changed, including the increase of MDR-TB patients, decreasing wellbeing of TB patients and a weak social support to TB and MDR -TB patients. It is time for a new law or amendments to the current law related to access to social assistance, in- and after treatment rehabilitation and other mechanisms to ensure ethics and human rights of the patients."

In Kyrgyzstan, the Patients' Charter, although not officially adopted, "is used by CSOs and human rights activists, but only in cases of human rights violations", - according to one of the respondents. However, "many such cases of violations are not brought to the attention of the CSOs or human rights activists and thus remain unnoticed." The issue of stigma and discrimination in TB has been the top problem identified by CSOs in Kyrgyzstan.

In the Republic of Moldova, 50% of the respondents commented that there is a national law on rights and responsibilities of the patients. Some of the respondents noted that it is comparable to the Patients' Charter or referred to other general documents on patients' rights and

responsibilities, not focusing on TB only, e.g. the law on 'equal opportunities'.

In Romania, two respondents indicated that there is a document similar to the Patients' Charter, two others indicated that it does not exist and 5 responded that they did not know. This perhaps reflects the situation, typical not only to Romania, but to many other countries of the region, where the MDR-TB patients do not know their rights as TB patients: they experience not effective treatment for MDR-TB and they do not know about this situation, they do not know about the social support they are entitled to receive. On the other hand, the staff who may be involved in these problems are not aware there are human rights violated. This situation can be solved with the involvement of a stronger civil society in order to advocate for MDR-TB patients' human rights.

In Tajikistan, during an external review conducted by WHO, a member of TBEC in the position of WHO temporary adviser, noticed that the Patients' Charter was translated and exhibited in visited the hospitals and health centers. However, when the doctors were asked whether they used the Charter and how, the response was negative. Survey respondents from Tajikistan gave mixed answers (1-yes, 1-no and 1 'I don't know'), an additional small group interview with participation of a former patient indicated that the Charter was not used or known among the patients. In a nutshell, and applicable to more countries, officially a document can be translated and distributed, as is the case in Tajikistan, but if patients do not know about it and if health care workers are not made aware of the importance of the charter and are not trained to use it in daily work, then the charter remains a formality and not a useful document which allows for more engagement of the patients. Responses from Uzbekistan were inconclusive.

WHO routinely collects information from the countries of the European region about dissemination of the Patient's Charter and training medical staff to use the Charter, however at the time of this report validated data was not available. Bulgaria and Estonia did not report carrying out dissemination and training on the use of the Charter to WHO, while some other countries did.

Indicator 6.6.3 Number of Member States having carried out client satisfaction assessments in the TB services

Layer of analysis: 18 HPC and 15 HMDRC

Target: 18 HPC including 15 HMDRC

Source: Desk review

Progress until 2014: patient satisfaction assessment in the TB services in the past 5 years were conducted in – Armenia*, Azerbaijan*, Belarus*, Georgia*, Kazakhstan*, Romania and Turkey - 7 of the HPC (39% of the target), including 5 HMDRC marked with an asterisk (33% of the target). CSOs were involved in 43% of patient satisfaction assessments.

A client satisfaction assessment measures the quality of different services from the clients' (patients, their families, visitors etc.) perspective. The assessed aspects can range from the perceived or actual access of clients to TB diagnosis and treatment to their experiences of communication with the health providers.

Client satisfaction assessments were conducted in Armenia, Azerbaijan, Belarus, Georgia, Kazakhstan, Turkey and partially in Romania. Unfortunately in Georgia client satisfaction assessments have been discontinued. Only respondents from Azerbaijan and Belarus mentioned that CSOs were involved in client satisfaction assessments. Respondents from Moldova and Ukraine did not give a unanimous answer to the question about client satisfaction assessments and the respective documents could not be found. More details about this indicator are in Annex 1.7.

A success story and concerns

Out of eight indicators that particularly concerned the civil society, only one has been achieved it is the establishment of the regional multi-stakeholders coordination committee, sustainably funded, to assist in scaling up response to MDR-TB. The RCC-TB addresses the need for improved communication and coordination among a wide spectrum of stakeholders to achieve greater impact of TB prevention and control across the WHO European Region. While a number of coordinative bodies exist (some formal, some informal), the RCC-TB is envisaged as an "open-source" platform to facilitate and allow greater engagement with and among partners, stakeholders and affected communities.

RCC-TB Steering Committee holds conference calls every other month, and discusses advocacy opportunities as well as the RCC-TB's functioning. The main activity in the period of writing of the current report was the development of advocacy fact sheets on:

- Involvement of civil society organizations (CSOs) and communities in TB care in the European region (link)
- TB-HIV integration (link)
- Ambulatory models of care (link)

RCC-TB currently consists of only six members and needs to be more active in order to attract more members. The main reason for a limited membership, quoted by the RCC-TB member was that "the people so far do not see the added value of joining such a mechanism".

The RCC-TB is a synergistic network with open membership; for additional information or how to engage and become a member, contact: tuberculosis@euro.who.int

The establishment of the RCC-TB Steering Committee is a good start and the main success so far, in terms of the civil society related indicators of the consolidated action plan. **The main concern is that after almost three years of implementation, not all countries (Table 3) of the region have achieved the other seven indicators related to civil society and patients' involvement, advocacy and patients' rights.**

Table 3. Percentage of HPCs and HMDRCs achieving civil society related indicators

N	Indicator	Number and % of 18 **HPCs** which achieved this indicator	Number and % of 18 HPCs which achieved this	Number and % of 15 **HMDRCs** which achieved this	Number and % of 15 HMDRCs which achieved this

		according to TBEC information	indicator according to preliminary WHO information	indicator according to TBEC information	indicator according to preliminary WHO information
6.4.2	Number of Member States with a national Stop TB Partnership up and running with meaningful involvement of all stakeholders	5 counties or 28%	not available	3 counties or 20%	not available
6.5.1	Number of Member States providing knowledge, attitudes and practice relevant to TB study/ies	15 counties or 77%	94% or 17 out of 18 countries (data of 2010, data for Rep of Moldova from 2012)	11 counties or 73%	100% or 15 out of 15 countries (data of 2010, data for Rep of Moldova from 2012)
6.5.2	Number of Member States with a developed and fully funded national ACSM strategy and work plan	0	not available	0	not available
6.5.3	Number of national Stop TB Partnerships, including patients' associations	5 counties or 28%	not available	3 counties or 20%	not available
6.5.4	Number of Member States that financially support nongovernmental organizations active in TB control with specific emphasis on hard-to-reach populations	2 counties or 11%	not available	2 counties or 13%	not available
6.6.1	Number of Member States with a Patients' Charter in place to ensure ethics and human rights	3 counties or 17%	Not comparable with TBEC results	3 counties or 20%	Not comparable with TBEC results
6.6.3	Number of Member States having carried out client satisfaction assessments in the TB services	7 counties or 39%	not available	5 counties or 33%	not available

Table 3 shows that the best performance is in (a) conducting KAP surveys and (b) client satisfaction surveys. The worst performance is in (c) having a developed and fully funded

national ACSM strategy and work plan and (d) availability of financial support from the state to non-governmental organizations active in TB control with specific emphasis on hard-to-reach populations. Preliminary, i.e. not verified, information had kindly been shared by the WHO Regional Office for Europe for the purpose of this report, some information was not available because it was not routinely collected.

Conclusions and recommendations

There are five main conclusions based on the results of the monitoring of consolidated action plan's implementation.

1. First, the collaboration at the level of the countries, including exchange of information, between the government and CSOs and among the local and international organizations appears limited, potentially leading to inefficiencies: gaps or duplication in TB response. Less than a quarter of the countries in the region have the national Stop TB Partnership up and running with meaningful involvement of all stakeholders.
   Limited information exchange and collaboration can also be seen in the considerable variance in the knowledge of the survey respondents about the different activities relevant to TB and CSOs in their countries.

2. Participation of people affected by TB in the national Stop TB Partnerships remains insufficient. There are only five national partnerships, which include patients or patients' organizations. In these conditions it is difficult to ensure advocacy for program improvements, such as more patient centered care, development of effective treatment adherence strategies and service integration. Increasing patients' representatives in partnerships will provide the necessary insights regarding the ongoing TB response and increase the planned activities' chances of success.

3. In the past five years more than three quarters of the countries have conducted KAP and client satisfaction surveys, while none of the countries have a costed ACSM strategy and work plan. KAP survey results have to be widely disseminated.
   Conducting KAP and client satisfaction surveys show a good start for planning, implementing, monitoring and evaluating activities conducted in the community. However, the absence of the coordinated, fully funded and implemented advocacy, communication and social mobilization activities renders the KAP and client satisfaction surveys mostly useless if their findings are not translated into action.

4. The use of Patients' Charter or national equivalents in order to ensure ethics and human rights has been reported by respondents from two HPCs only.
   Participation of people affected by TB remains limited and then it is not surprising that the use of either international Patients' Charter or national equivalents in order to ensure ethics and human rights is limited too. Even if the international Patients' Charter is printed, distributed to TB facilities and the TB staff are trained to use the Charter, it is not yet a guarantee that its use will be for better ethics and an improvement in the human rights situation around access to TB diagnosis and care.

5. CSOs in the HPCs are currently dependent on the Global Fund. This is further complicated by decreasing donor assistance in the European region and a high

dependence of TB projects implemented by CSO on donor funding, while the role of CSOs in facilitating case finding and supporting adherence is still mostly not recognized by their governments. This translates in the absence of domestic funding and social procurement. For many countries of the region the next Global Fund grant for TB may well be the last one.

The following recommendations are given by the TB Europe Coalition:

To the CSOs

- Ensure participation in national TB platforms, and joining regional networks in order to:
  - share information
  - coordinate and participate in policy dialogue
  - step up the advocacy for increasing domestic financing to TB response
  - promote patients' rights and ethics by the real use of the Patients' Charter or its national equivalent.
- Reach out to NTPs and demonstrate the added value of CSOs being involved in the design and implementation of TB interventions.
- Build sustainable relationships with other CSOs (via national TB civil society platform), especially those concerned with HIV that are engaged in other health issues and also in related sectors, such as gender and human rights.
- Advocate for the community initiatives such as patients' groups' participation in decision-making in national Stop TB Partnerships and in CCMs when it comes to the design, implementation and monitoring of TB interventions. Ensure that there is a two-way communication between the key affected populations and TB patients and their representatives in the CCM.

To National TB Programs

- Recognise CSOs and affected communities as respected partners across all components of national TB programmes.
- Systematically consult, involve and empower CSOs and affected communities in the development of National Strategic Plans.
- Include CSOs and affected communities in the design and implementation of all TB control activities. Shift tasks to CSOs and educate them first: train CSOs on TB infection control, community-based TB care and case management
- Ensure CSOs and affected communities are represented in all existing mechanisms of collaboration for better TB control, such as the Country Coordinating Mechanisms (CCM).
- Provide CSOs and affected communities with the support needed to carry out their essential activities and coordination among themselves. Include CSOs, which provide TB services, into supporting supervision and visit them when NTPs go on supervision visits to state TB service providers
- Identify together with CSOs the areas where CSOs are better positioned to reach out to vulnerable population groups and develop a joint implementation plan. See NTP-CSO collaboration paper by TBEC for more details (link)

To the CCMs

- Involve CSOs, key affected populations and TB activists in the country dialogues, in the development of National Strategic Plans and Concept Notes, as outlined in the New Funding Model of the Global Fund. Commit to the plans of TB constituencies' engagement. These activities are eligible for CCM funding.
- Ensure true and effective representation of CSOs and affected communities by feedback mechanism and plans of constituencies' engagement, transparent selection of CCM members from the CSO and people living with the diseases constituencies. Involve them in the Oversight and other key bodies within the CCM and build their capacity as CCM members.

To the National governments/Ministries of Health

- Urgently speed up the social procurement schemes to provide CSOs and affected communities with the funding needed to participate in TB response, based on their unique knowledge of key populations affected by TB.

To technical partners and international organizations

- Work HIV-service organizations, human right organizations and those working with key TB affected populations to strengthen their capacity to address TB through referral, advocacy and community-based TB treatment and care.
- Fund CSOs, many of whom are trained in TB and have established relations with populations affected by TB, but do not have access to funds in order to participate in TB response.
- Include local CSOs, not only governmental structures, in your sustainability plans to continue the community-based work and maintain advocacy after your programs phase out.

To the EU institutions - political leadership

- Demonstrate stronger regional political leadership on TB in the EU and the greater European region.
- Recognize TB and M/XDR-TB as a serious cross-border health threat.
- Help support local CSOs to advocate for health rights and accountability.

To the WHO - consolidated action plan's new commitments

- Conduct information gathering on all indicators – not only the core indicators - via desk reviews where routine reporting is not conducted.
- Ensure that indicators related to the involvement of civil society and communities are systematically included in areas covered during NTP Reviews.
- Publish the results separately from the yearly surveillance report in order to make progress or a lack thereof more visible.
- Systematically involve one civil society actor and one community representative in each National TB Programme Review to evaluate progresses on involvement of civil society and communities in policy dialogue and where relevant service provision.

Annex 1.1. Number of Member States with a national Stop TB Partnership up and running with meaningful involvement of all stakeholders

country	national Stop TB Partnership exists	functioning	If all stakeholders are represented (yes, no, undetermined)/ recommendations regarding who else should be involved	Comments given by respondents
Armenia*	No	-	-	National TB Control Programme, CCM
Azerbaijan*	Undetermined There is a TB Working Group at the CCM consisting of CSOs. There is also an interagency working group including CSOs, NTP, MOH.	Meets with regularity. Main recent activities include community mobilization, writing proposals to the Global Fund	Yes / European Commission, MOH, Global Fund, TBEC, STBP, local CSOs, military sector, patients and their families	
Belarus*	No	-	-	State program "Tuberculosis" is carried out by the MOH with participation of the civil society
Bulgaria*	No	-	-	CCM There is a lack of TB patients' organizations and TB CSOs
Estonia*	No	-	-	
Georgia*	No	-	-	CCM
Kazakhstan*	No	-	-	CCM, NTP
Kyrgyzstan*	Undetermined	-	Yes/ Private sector, patients	Country Coordination Board does not include

	There is an ACSM thematic group that needs activation; there is an advocacy group lead by MSF that does not include local CSOs and there is a communication group. There is a CCM that is yet to strengthen its links with KAP and PLWD		organizations, CSOs, donors, MOH department of drug procurement, family doctors' association, CCM members, members of relevant Parliamentary committees	local CSOs, TB and HIV Thematic Working Group
Latvia*	No	-	-	-
Lithuania*	No	-	-	Once active national Stop TB Partnership is no longer in existence
Republic of Moldova*	Yes National Platform of CSO involved in TB	Meets quarterly. Main recent activities include training on TB, advocacy for linezolid for compassionate use	Yes/ Key affected communities' representatives such as people who use drugs (PWUD)	The Platform includes 2 TB CSOs and 8-9 HIV CSOs, the Platform is a CCM member. Created recently in 2013
Romania	Yes Romanian Stop TB partnership	Meets 2-3 times a year; Main recent activities include celebration of the World TB Day (WTBD), media campaign	No/ No examples were given	Partnership exists at least at the conceptual level, more effort needs to be put in order for it to have sustained activities, rather than calling together various orgs in ad hoc efforts
Russian Federation*	No	-	-	National Tuberculosis Control Program under the MOH
Tajikistan*	Yes TB Coordination committee at the Ministry of Health and Social	Meets quarterly; Advocacy for prohibiting of over the counter sale of	Yes/ patients' group	Some respondents said that TB patients organizations are represented at the Committee some that

	Protection. Recently a Stop TB partnership was established	first line TB drugs, organization of the WTBD		they are not represented
Turkey	Yes Turkey's National Tuberculosis Association	Yes	Yes	
Turkmenistan	Undetermined	No information	No information	One respondent indicated presence of a national Stop TB Partnership but did not provide any additional information
Ukraine*	Yes Coalition of organizations Stop TB Together	Meetings once every two years, in 2013 there was an analysis of the effectiveness of a regional TB program	Yes	Some respondents mention CCM, provincial CCM, Foundation "Ukrainians against Tuberculosis"
Uzbekistan*	No	-	-	There are no national TB CSOs.

* high MDR country

Layer of analysis: 18 HPC (high priority countries) 15 HMDRC[2] (high MDR priority countries).

Target: 18 HPC including 15 HMDRC

Actual in 2014: 5 of the HPC (28% of the target), including 3 HMDRC (20% of the target) have a Stop TB Partnership or a similar structure.

[2] High-burden MDR-TB countries were selected on the basis of an estimated absolute number of at least 4000 MDR-TB cases arising annually and/or at least 10% of all newly registered TB cases estimated with MDR-TB, as of 2008. The 15 countries of the WHO European Region with a high MDR-TB burden are Armenia, Azerbaijan, Belarus, Bulgaria, Estonia, Georgia, Kazakhstan, Kyrgyzstan, Latvia, Lithuania, Republic of Moldova, Russian Federation, Tajikistan, Ukraine, Uzbekistan.

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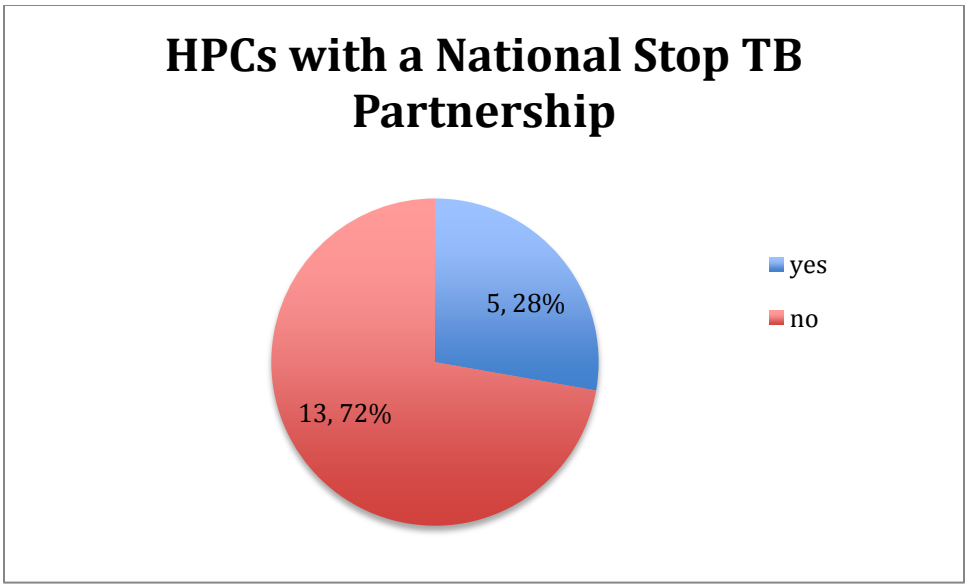
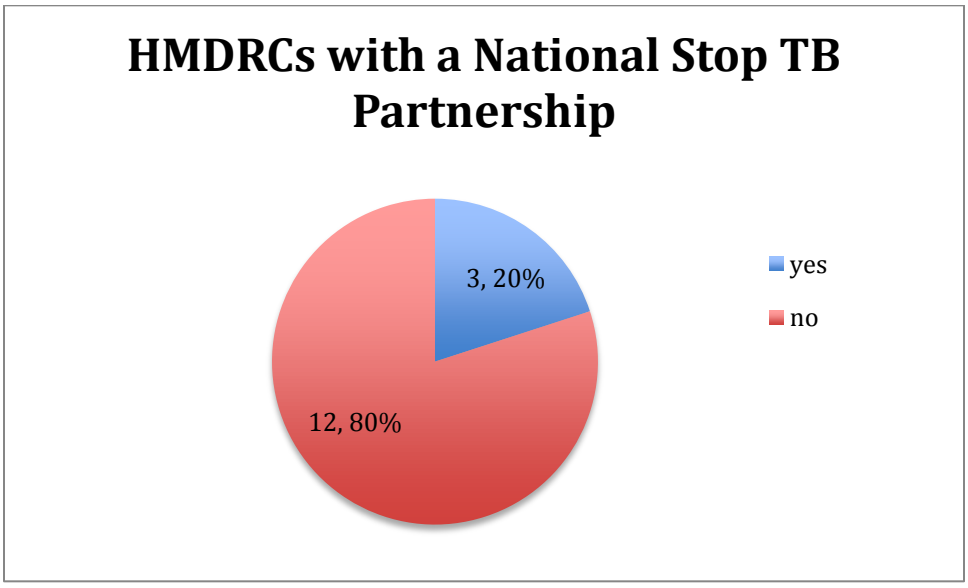

HPCs with a National Stop TB Partnership
5, 28%
13, 72%
yes
no

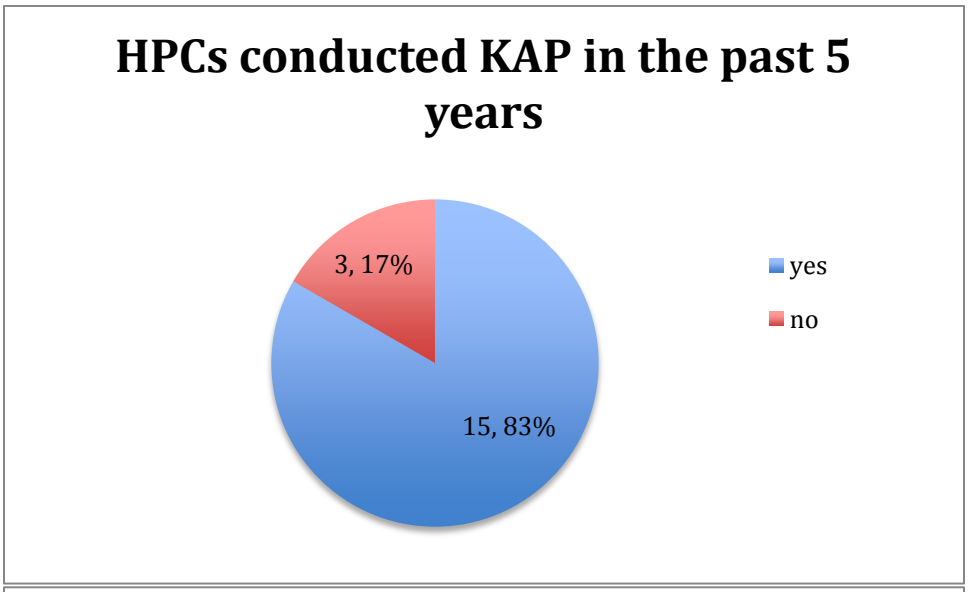

HMDRCs with a National Stop TB Partnership
3, 20%
12, 80%
yes
no

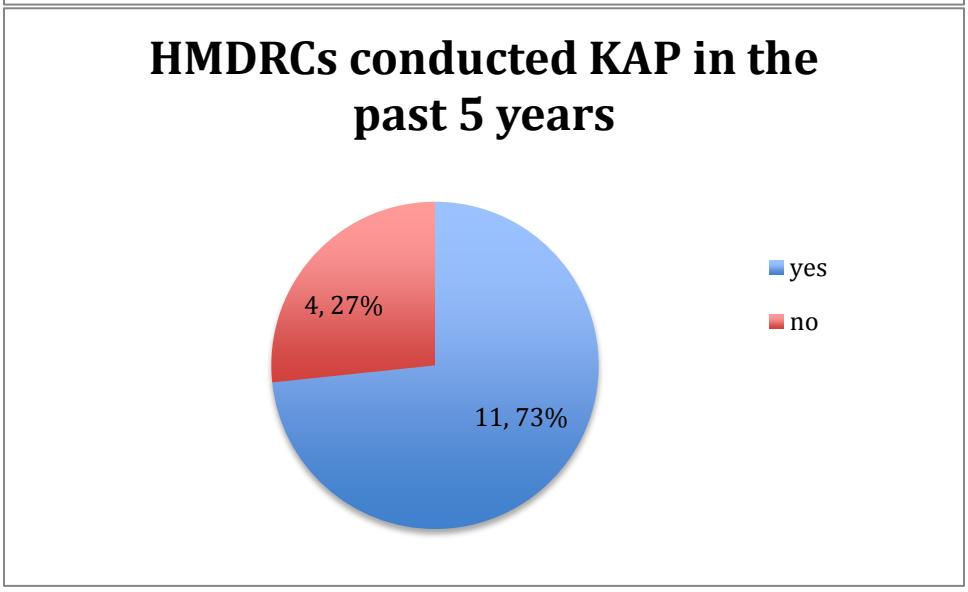
Annex 1.2. Number of Member States providing knowledge, attitudes and practice relevant to TB study/ies

country	TB-related knowledge, attitudes and practice study in the past 5 years
Armenia*	Yes
Azerbaijan*	Yes
Belarus*	Yes
Bulgaria*	Yes
Estonia*	No
Georgia*	Yes
Kazakhstan*	Yes
Kyrgyzstan*	Yes
Latvia*	No
Lithuania*	No
Republic of Moldova*	Yes
Romania	Yes
Russian Federation*	Yes
Tajikistan*	Yes
Turkey	Yes
Turkmenistan	No information
Ukraine*	Yes
Uzbekistan*	No

* high MDR country

** Patients' satisfaction survey is planned by KNCV (focusing on the outpatient care) in September 2014, KNCV plans to involve other CSOs but currently does not have the funds for such involvement.





Annex 1.3. Number of Member States with a developed and fully funded national ACSM strategy and work plan

country	a joint planning of advocacy, communication and social mobilization (ACSM) and MDR-TB activities took place	There is an ACSM strategy	ACSM strategy is funded	There is an ACSM work plan	ACSM work plan is funded
Armenia*	No	Yes	Partially or not funded	No	No
Azerbaijan*	Yes	Yes	No	Yes	No
Belarus*	No	Yes	No	Yes	No
Bulgaria*	No	Yes	Partially	Yes	Partially
Estonia*	No	No	-	No	-
Georgia*	Yes	Yes	Partially	Yes	Undetermined
Kazakhstan*	Yes	Yes	Partially	Yes	Partially
Kyrgyzstan*	Yes	Yes	Partially	Yes	Partially
Latvia*	Undetermined	Undetermined	-	No	-
Lithuania*	No	Undetermined	No	No	-
Republic of Moldova*	Yes	Yes	No/Partially	Yes	No/Partially
Romania	No	Undetermined	Undetermined	Undetermined	Undetermined
Russian Federation*	No	No	-	No	-
Tajikistan*	Yes	Yes	Partially	Yes	Partially
Turkey	Undetermined	Yes	Yes	No	-

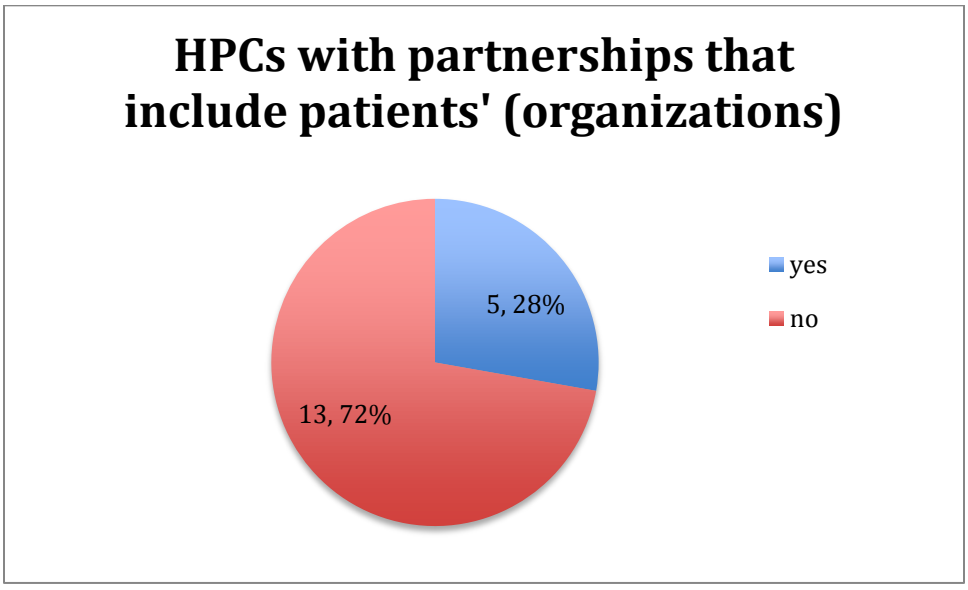
Turkmenistan	Undetermined	Undetermined	Undetermined	Undetermined	Undetermined
Ukraine*	Yes	Yes	No/Partially	Undetermined	No/Partially
Uzbekistan*	Yes	Yes	No	No	-

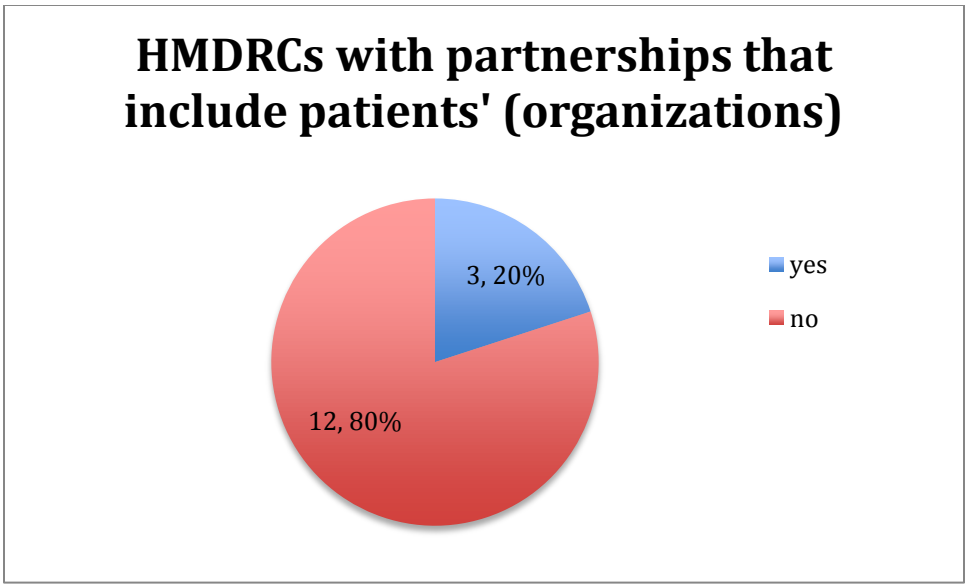
* high MDR country

Annex 1.4. Number of national Stop TB Partnerships, including patients' associations

country	national Stop TB Partnership exists	Includes TB patients or TB patients organisation
Azerbaijan*	Undetermined	No
Republic of Moldova*	Yes National Platform of CSO involved in TB	Includes one organization of ex patients
Romania	Yes Romanian Stop TB partnership	Includes organization of ex patients
Tajikistan*	Stop TB Partnership Tajikistan	Yes, it is initiated by TB activists
Turkey	Yes Turkey's National Tuberculosis Association	Includes patients organization
Ukraine*	Yes Coalition of organizations Stop TB Together	More than 30 organizations including (ex-) patients

* high MDR country



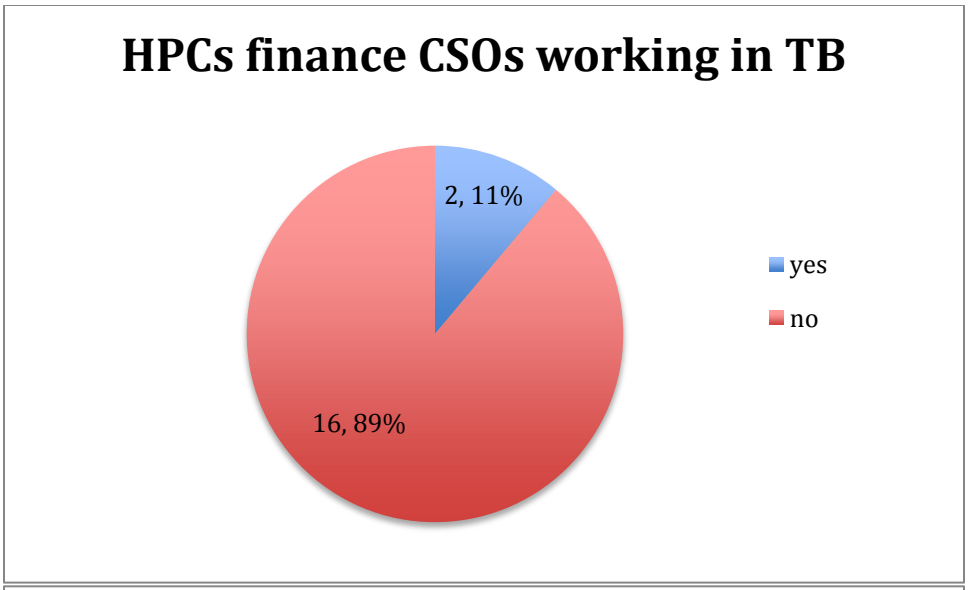

HMDRCs with partnerships that include patients' (organizations)
3, 20%
12, 80%
yes
no

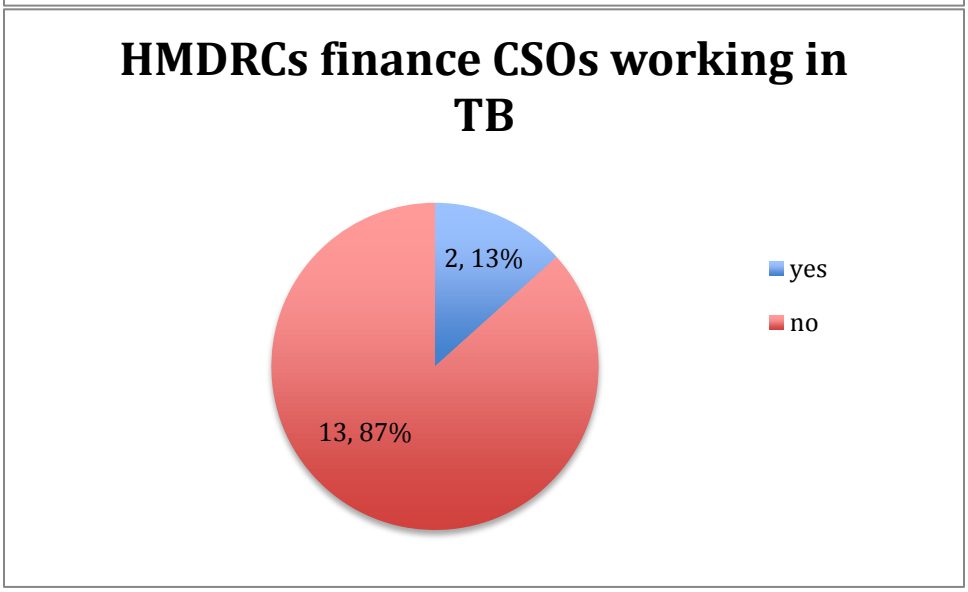
Annex 1.5 Number of Member States that financially support nongovernmental organizations active in TB control with specific emphasis on hard-to-reach populations

Country	Financial support from GOV to CSOs	How?	Any support from GOV to TB advocates	How?	Any support from GOV to treatment supporters	How?
Armenia*	No	-	No	-	Yes	Political commitment, basic salaries, opportunity for short working day and longer paid annual leave
Azerbaijan*	No	-	Yes	Through discussion and sharing the information during meetings, round tables and trainings	Yes	Through discussion and sharing the information during meetings, round tables and trainings
Belarus*	No	-	No	-	Undetermined	Adherence activities, salaried for psychologists and social workers
Bulgaria*	Yes	Financial support to 15 CSOs (€100,000)	No	-	No	-
Estonia*	No	-	No	-	No	-
Georgia*	No	-	No	-	No	-
Kazakhstan	Yes	~€605,000	Yes	-	Yes	DOT providers and treatment

*						support groups
Kyrgyzstan*	Undetermined	Support to 5 CSOs in the past	No	-	No	-
Latvia*	No	-	No	-	No	-
Lithuania*	No	-	No	-	No	-
Republic of Moldova*	No	-	No	-	No	-
Romania	No	-	No	-	No	-
Russian Federation*	No	-	No	-	Yes	Social workers in some regional take part in incentive programs
Tajikistan*	No	-	No	-	Undetermined	
Turkey	Undetermined		Undetermined		Undetermined	
Turkmenistan	Undetermined		Undetermined		Undetermined	
Ukraine*	No	-	No	-	No	Social workers have access to TB institutions, they are not financially supported by the GOV
Uzbekistan*	Undetermined		Undetermined		Undetermined	

* high MDR country


HPCs finance CSOs working in TB
2, 11%
16, 89%
yes
no

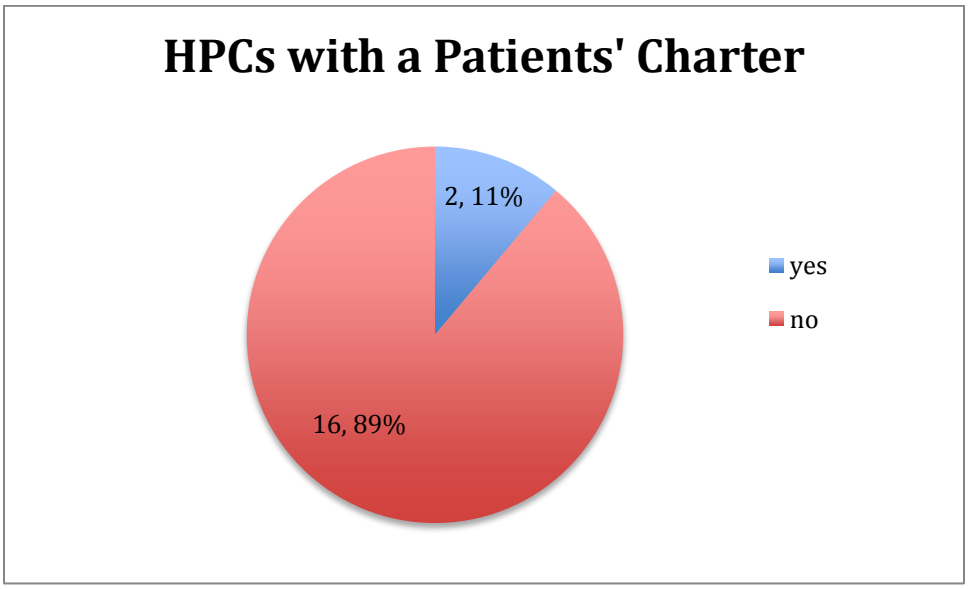

HMDRCs finance CSOs working in TB
2, 13%
13, 87%
yes
no

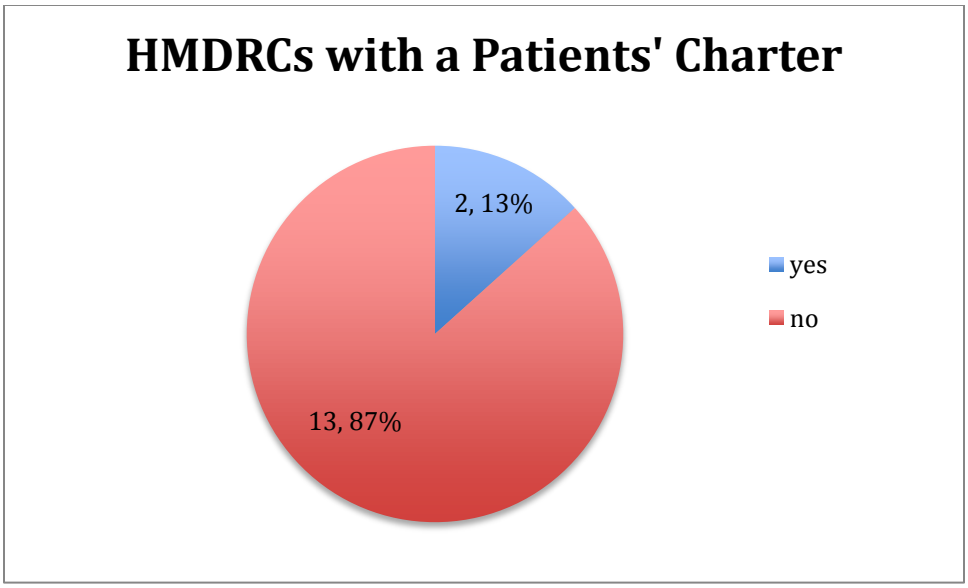
Annex 1.6. Number of Member States with a patients' charter in place to ensure ethics and human rights

country	patients' charter in place	Notes, clarification
Armenia*	No	
Azerbaijan*	No	
Belarus*	No	There are rights and responsibilities of patients in the TB Law, but they are more of a formality
Bulgaria*	Yes	
Estonia*	Yes	The main principles of Patients Charter used for dialogue with patients and contacts
Georgia*	No	One of the 14 respondents indicated that "TB Patient's Charter is translated and available"
Kazakhstan*	No	
Kyrgyzstan*	No	
Latvia*	No	
Lithuania*	No	
Republic of Moldova*	Undetermined	
Romania	Undetermined	
Russian Federation*	Undetermined	
Tajikistan*	No	One respondent pointed out that the national strategic plan addresses the human rights and ethics questions
Turkey	Undetermined	

Turkmenistan	Undetermined	
Ukraine*	No	Only a few know about the Patients Charter, one CSO distributed the Charter to decision makers, but the document was never adopted.
Uzbekistan*	Undetermined	Patients Charter was translated to Uzbek language and distributed according to one respondent, this information received in the interviews did not confirm the Charter's use in practice

* high MDR country

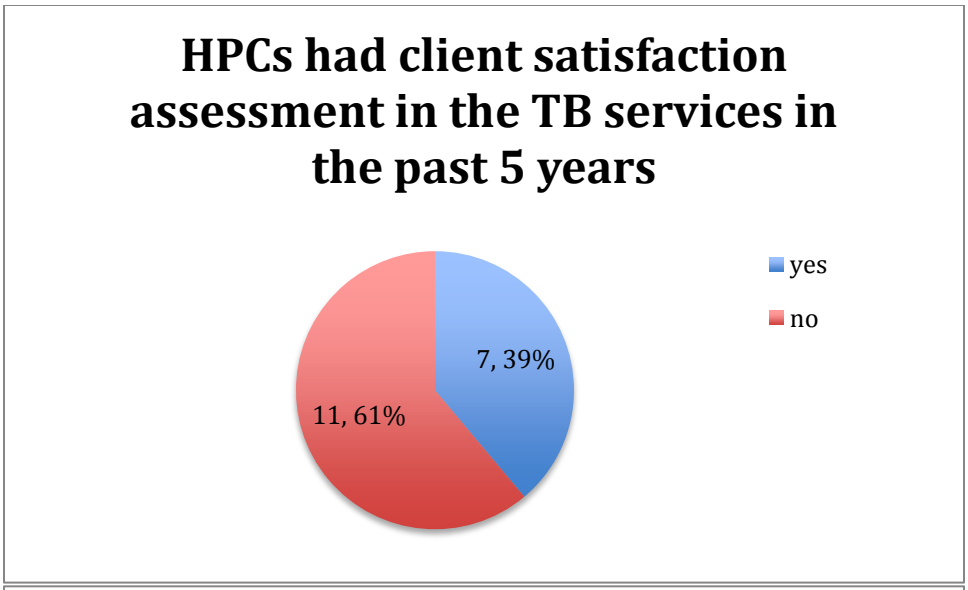


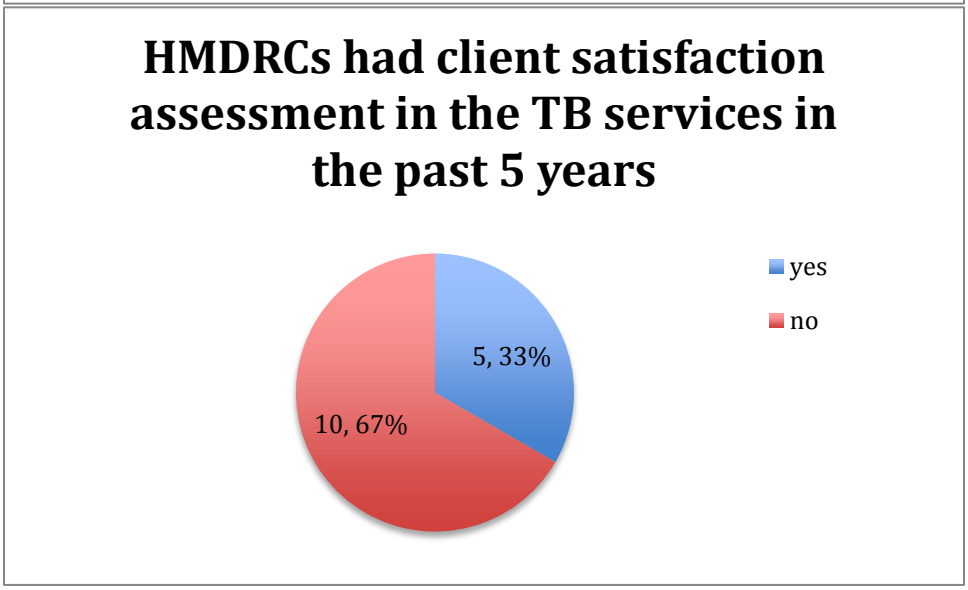

HMDRCs with a Patients' Charter
2, 13%
13, 87%
yes
no

Annex 1.7. Number of Member States having carried out client satisfaction assessments in the TB services

country	client satisfaction assessment in the TB services in the past 5 years	have CSOs been involved in this assessment
Armenia*	Yes	No information
Azerbaijan*	Yes	Yes
Belarus*	Yes	Yes
Bulgaria*	No	-
Estonia*	No	-
Georgia*	Yes (but currently discontinued)	No
Kazakhstan*	Yes	Undetermined
Kyrgyzstan*	No (planned)**	-
Latvia*	No	-
Lithuania*	No	-
Republic of Moldova*	No/Undetermined	-
Romania	Yes (part of ACSM strategic document)	-
Russian Federation*	No	-
Tajikistan*	No	-
Turkey	Yes	No information
Turkmenistan	No information	No information
Ukraine*	Undetermined	Undetermined
Uzbekistan*	No	-

* high MDR country


HPCs had client satisfaction assessment in the TB services in the past 5 years
yes
no
7, 39%
11, 61%


HMDRCs had client satisfaction assessment in the TB services in the past 5 years
yes
no
5, 33%
10, 67%

Annex 1.8. Advocacy, Communication and Social Mobilization

Advocacy, communication and social mobilization (ACSM)

Advocacy, communication and social mobilization (ACSM) is a term that describes a set of activities aimed at encouraging care-seeking behaviour, providing education on the signs and symptoms of TB, providing education on where to go for TB testing and treatment, increasing knowledge about risk factors for TB, combating stigma, providing a channel for afflicted individuals and communities to voice needs and concerns, encouraging community action, and calling for increased political and financial support for local, national and international action.

E3.15a Were NGOs and other relevant stakeholders outside the NTP involved in planning and implementing ACSM activities?

- (●) Yes
- ( ) No

E3.15b Have you conducted a Knowledge, Attitudes and Practices (KAP) study or similar survey on TB?

- ( ) Yes
- (●) No

E3.15c If Yes, was the last KAP study used to:

Measure a baseline in order to perform a follow up ACSM impact evaluation at a later stage?

- ( ) Yes
- ( ) No

Design appropriate ACSM or service-related activities based on the findings?

- ( ) Yes
- ( ) No

Patients' Charter for Tuberculosis Care

E3.15d Has the Patients' Charter (http://www.who.int/tb/publications/2006/patients_charter.pdf) been printed and disseminated to TB treatment centres?

- ( ) Yes
- (●) No

E3.15e Have TB personnel been trained on the use of the Patients' Charter?

- ( ) Yes
- (●) No

References

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