

# FALLING SHORT:

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

STEFAN · BISERCANI HOSPITAL · ROMANIA

*Stefan sits on his bed at Biserani hospital, Romania. Stefan has lost both his parents and his wife to drug resistant TB. In April 2013, Stefan's wife decided to stop taking her pills due to the severity of the side effects and returned to her home on the Moldovan border where she later died. Stefan is determined to complete his treatment and is no longer contagious. He does not know what he will do when he leaves Biserani; he has no job to go to and nowhere to live.*

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Michaela was diagnosed with MDR-TB in July 2013, shortly after giving birth to her second son and is now 7 months into her 2 year long treatment for MDR-TB. Without financial support from the government for childcare, Michaela has had to rely on friends in Moldova to look after her children while her husband looks for work in London.

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## ACRONYMS

<b>ACSM</b>	Advocacy, Communication and Social Mobilisation	<b>MAP</b>	Consolidated Action Plan to Prevent and Combat M/XDR-TB 2011-2015
<b>AIDS</b>	Acquired Immune Deficiency Syndrome	<b>MDR-TB</b>	Multi Drug-Resistant Tuberculosis
<b>CCM</b>	Country Coordinating Mechanism	<b>NFM</b>	New Funding Model
<b>CSS</b>	Community Systems Strengthening	<b>NTP</b>	National Tuberculosis Programme
<b>EECA</b>	Eastern Europe and Central Asia	<b>PWID</b>	People Who Inject Drugs
<b>EU</b>	European Union	<b>RCC-TB</b>	Regional Collaborative Committee on Tuberculosis
<b>Global Fund</b>	The Global Fund to Fight AIDS, Tuberculosis and Malaria	<b>TAG</b>	Technical Advisory Group
<b>HIV</b>	Human Immunodeficiency Virus	<b>TB</b>	Tuberculosis
<b>KAP</b>	Knowledge, Attitude and Practice Studies	<b>WHO</b>	World Health Organisation
		<b>XDR-TB</b>	Extensively Drug-Resistant Tuberculosis

## BACKGROUND

Tuberculosis (TB) is one of the deadliest communicable diseases worldwide, killing 1.3 million people each year.<sup>1</sup> Additionally, drug-resistant strains of TB that are both difficult and more expensive to treat are increasingly prevalent. Drug resistant strains of TB are not unique to developing countries. Rising rates of multi and extensively drug-resistant TB (M/XDR-TB) are a real public health threat across the 53 countries that make up the World Health Organisation (WHO) European Region, and are a threat that can no longer be ignored.

The problem of M/XDR-TB persists throughout the entirety of the WHO European Region (hereafter referred to as the European Region) but the impact of the disease is most substantial in Eastern Europe and Central Asia (EECA).<sup>2</sup> Over two decades ago, the economic collapse that accompanied the fall of the Soviet Union laid the foundations for the TB epidemic to thrive in EECA. Unemployment and poverty sky-rocketed, and state TB health and social services collapsed, setting back decades of progress towards the elimination of TB and fostering the creation of huge increases in drug-resistance due to interrupted and poor treatment.

At present in the European Region there remain an estimated 360,000 people newly diagnosed with TB every year, 40,000 of whom die from the disease.<sup>4</sup> Additionally, the Region has one of the highest burdens of multidrug-resistant TB (MDR-TB) in the world. **Despite representing only 13 percent of the world's population, the Region makes up a quarter of the global MDR-TB burden – an estimated 74,000 MDR-TB cases each year. Fifteen of the twenty-seven WHO high MDR-TB burden countries are situated in EECA.** Moreover, the European Region has **lower cure rates than any other WHO region.**<sup>5</sup> Most alarmingly, the European Union's (EU) cure rate is lower than the one of the "wider" WHO European Region, with only 33 percent of M/XDR-TB cases successfully treated.<sup>6</sup> **This means that two-thirds of all individuals who get M/XDR-TB in the EU are not cured.**

### MDR-TB

Multidrug-resistant tuberculosis (MDR-TB) is a form of TB that does not respond to at least isoniazid and rifampicin, the two most powerful anti-TB drugs. In 2010, only 48% of MDR-TB patients were cured or successfully completed their treatment.<sup>7</sup>

### XDR-TB

Extensively drug-resistant tuberculosis (XDR-TB) is resistant to isoniazid and rifampicin, to any of the fluoroquinolone drugs and to at least one of the three injectable second-line drugs (amikacin, capreomycin or kanamycin).<sup>8</sup>

1 WHO (2013) *Global Tuberculosis Report 2013*, Geneva: World Health Organisation

2 WHO European Region countries: Albania; Andorra; Armenia; Austria; Azerbaijan; Belarus; Belgium; Bosnia and Herzegovina; Bulgaria; Croatia; Cyprus; Czech Republic; Denmark; Estonia; Finland; France; Georgia; Germany; Greece; Hungary; Iceland; Ireland; Israel; Italy; Kazakhstan; Kyrgyzstan; Latvia; Lithuania; Luxembourg; Malta; Monaco; Montenegro; Netherlands; Norway; Poland; Portugal; Republic of Moldova; Romania; Russian Federation; San Marino; Serbia; Slovakia; Slovenia; Spain; Sweden; Switzerland; Tajikistan; The former Yugoslav Republic of Macedonia; Turkey; Turkmenistan; Ukraine; United Kingdom of Great Britain and Northern Ireland; Uzbekistan.

3 In this report, we focus on the following EECA countries due to their high burden of TB : Bulgaria, Estonia, Latvia, Lithuania, Romania (EU member states); Armenia, Azerbaijan, Belarus, Georgia, Moldova, Ukraine (Eastern Partnership Countries); Kazakhstan, Kyrgyzstan, Tajikistan, Turkmenistan, Uzbekistan (Central Asian Countries); the Russian Federation.

4 WHO (2013) *Global Tuberculosis Report 2013*, Geneva: World Health Organisation

5 <http://apps.who.int/gho/data/view.main.57196?lang=en>

6 ECDC (2014) *TB Surveillance Report*, Stockholm: European Centre for Diseases Prevention and Control

7 WHO (2013) *Global Tuberculosis Report 2013*, Geneva: World Health Organisation

8 Fluoroquinolones are a broad spectrum of antibiotics that have become indispensable in the treatment of DR-TB. They include the following, in order of potency: moxifloxacin, gatifloxacin, levofloxacin, ofloxacin, and ciprofloxacin.

REGIONAL COLLABORATIVE COMMITTEE ON TB

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Efforts to tackle M/XDR-TB in the European Region are still falling short. While progress and tangible achievements have certainly been made, M/XDR TB treatment outcome in the region remains far from international targets or even the Region's own ambition as articulated in numerous declarations and action plans.<sup>9,10</sup> A number of challenges such as health service delivery, financing, and health system governance still undermine progress and hinder further achievements in the region:

- **Political commitment to tackle the disease remains inadequate.** Both national and regional decision-makers have not yet paid sufficient attention to M/XDR-TB. There is an urgent need for greater political leadership both nationally and regionally to strengthen health systems and introduce health financing reforms. Regional representatives in the EU along with national governments in the European Region must come together in order to facilitate more effective cooperation between countries and scale up the response to the M/XDR-TB epidemic.
- **Sustainable domestic financing of the TB response.** The Global Fund to Fight AIDS, TB and Malaria (the Global Fund) has been playing a significant donor role in EECA since 2002. Through Global Fund investments, countries have been supported in developing enabling environments and have strengthened health and community systems allowing the region to make considerable progress against HIV and TB. However, as a result of the Global Fund's recent efforts to ensure that funding is focused on low-income and high-disease burden countries, future funding in EECA will likely be significantly lower than it is now.<sup>11</sup> It is therefore crucial that domestic and regional representatives respond to the phasing out of international financial support. They must establish mechanisms for sustainable financing of TB care embedded in their national budget plans, thereby ensuring that progress does not stall and the fight against TB and HIV accelerates.
- **Lack of patient-centered approaches and the limited involvement of civil society.** In many settings, healthcare systems in the region still rely on outdated and vertical hospitalised systems. Health reforms must adopt integrated and patient-centered care to curb the spread of M/XDR-TB, reduce costs and bring the entire continuum of care closer to patients and communities. TB treatment must extend beyond the physical body and include access to social and psychological support as an important aspect of care. Civil society is gradually being recognised as an important stakeholder to involve in the provision of care. Civil society should be involved in providing psychosocial support and care for those affected by M/XDR-TB and ensure that socially vulnerable groups, such as the Roma community, homeless people, former prisoners, sex workers, or people who inject drugs, have access to TB treatment and care. There is still progress to be made in ensuring that civil society are supported in order to more effectively participate in TB care and in contributing to the fight against TB more broadly.

In response to the alarming problem of M/XDR-TB and to the challenges outlined above, the WHO Regional Office for Europe launched the **Consolidated Action Plan to Prevent and Combat M/XDR-TB 2011-2015 (MAP)** in 2011. The MAP, endorsed by the 53 Member States of the European region, aims to contain the spread of M/XDR-TB by achieving universal access to prevention, diagnosis and treatment in all Member States by 2015. Major targets to be reached by 2015 include:

- Decreasing the proportion of MDR-TB cases among previously treated patients by 20 percentage points;
- Diagnose at least 85 percent of all estimated MDR-TB patients;
- Successfully treat at least 75 percent of all MDR-TB patients identified.<sup>12</sup>

As the major policy document in the European Region governing the response to M/XDR-TB, the MAP is central in addressing the M/XDR-TB epidemic. The MAP provides clear recommendations to countries on improving the involvement of civil society in TB programmes. This report will assess the progress made to ensure the involvement of civil society in the M/XDR-TB response in the European Region and specifically among the high priority and high burden countries of the Region.<sup>13</sup> While doing so, this report will also make recommendations to policy makers, technical partners, international organisations and civil society in order to ensure a holistic approach to the TB response.

9 The Berlin Declaration on Tuberculosis (2007) [online] available from: [http://www.euro.who.int/\\_data/assets/pdf\\_file/0008/68183/E90833.pdf](http://www.euro.who.int/_data/assets/pdf_file/0008/68183/E90833.pdf)

10 The Consolidated Action Plan to Prevent and Combat M/XDR-TB 2011-2015 (MAP)

11 Global Fund to Fight AIDS, TB and Malaria (2014) *Turning the Tide Against HIV and Tuberculosis Global Fund Investment Guidance for Eastern Europe and Central Asia*. Geneva: The Global Fund

12 The Consolidated Action Plan to Prevent and Combat M/XDR-TB 2011-2015 (MAP)

13 High priority and high burden countries: Armenia, Azerbaijan, Belarus, Bulgaria, Estonia, Georgia, Kazakhstan, Kyrgyzstan, Latvia, Lithuania, Republic of Moldova, Romania, Russian Federation, Tajikistan, Turkey, Turkmenistan, Ukraine, Uzbekistan

## THE ROLE OF CIVIL SOCIETY IN THE TB RESPONSE

### DEFINING CIVIL SOCIETY:

CIVIL SOCIETY is defined broadly to include a wide array of NON-GOVERNMENTAL, NOT-FOR-PROFIT AND VOLUNTARY ORGANISATIONS OR GROUPS who are working on TB or in other related areas (i.e. HIV, harm reduction, human rights, and minority or marginalised groups).

CIVIL SOCIETY also includes those who could have an impact in the fight against TB, including INDIVIDUAL ADVOCATES, PATIENT ORGANISATIONS, as well as key affected populations and communities.

The term "AFFECTED COMMUNITIES" refers to people directly or indirectly affected by the disease.

AFFECTED COMMUNITIES represent people who suffer from the disease and therefore possess unique knowledge on how to best address their needs in their countries and local contexts.

AFFECTED COMMUNITIES can include people at high risk of TB infection as well as those who bear a disproportionate burden of the impact of TB. Therefore, AFFECTED COMMUNITIES not only include TB patients (or former patients), their families and friends, but also, for example, health workers, prisoners, sex workers, migrants, the homeless, people who inject drugs, the Roma community and people living with HIV.

Civil society can play a transformative role in TB care and should be recognised as significant players in the TB response in the European Region. Often, civil society is embedded within communities and well placed to take on operational roles relating to detection and patient support. They can advocate for the interests of their members or the groups they represent, play an integral role in empowering key affected populations, help reduce stigma and discrimination, promote social and structural changes in the fight against TB, mobilise resources, advocate, and engage in policy dialogue.

In **Azerbaijan**, the involvement of civil society in patient follow-up, treatment adherence and psychosocial support has allowed the country to achieve some of best cure rates for M/XDR-TB in prisons in the region. The rate of loss to follow-up after release has been reduced to almost zero and the treatment success rate for new TB patients has increased to 88%.<sup>14</sup> Meanwhile, in **Bulgaria**, civil society has been contracted by the National TB Programme (NTP) to expand community awareness of TB and patient support.<sup>15</sup> Remove, Bulgaria has achieved a significant drop in TB incidence, almost halving the incidence rate to 32 per 100,000 over five years.<sup>16</sup> The NTP and health professionals acknowledge that the involvement of civil society in a systemic way has been a major contributor to this success. Hence, effective engagement of civil society has been reported and can be further replicated across the region. However, this will only happen when civil society is fully integrated into every level of the M/XDR-TB response. This includes involving civil society in the development of relevant policies and national strategic plans and ensuring their support in the delivery and monitoring and evaluation of TB services.

### EXAMPLES OF INVOLVEMENT OF CIVIL SOCIETY IN THE REGION:

▷ IN KAZAKHSTAN, the government provides financial support for civil society to form treatment support groups.

▷ IN BELARUS social procurement by civil society working on M/XDR-TB is being considered.

▷ IN ARMENIA, AZERBAIJAN AND UKRAINE, governments provide non-financial support to patient advocates, such as information sharing and invitations to relevant meetings.

▷ WHILE IN KYRGYZSTAN there is a possibility to use the existing approach of social procurement, in terms of Government outsourcing to civil society so they are able to deliver medicines to patients. However, the Ministry of Health does not yet utilize it.

▷ IN TAJIKISTAN, the government is piloting community-based TB treatment and care. Joint activities between the Ministry of Health and civil society are costed in the national working plan, which is a helpful step forward yet remains to be implemented.

14 [http://www.stoptb.org/news/stories/2014/ns14\\_053.asp](http://www.stoptb.org/news/stories/2014/ns14_053.asp)

15 WHO (2013) *Best Practices in Prevention, Control and Care for Drug-Resistant Tuberculosis: A resource for the continued implementation of the Consolidated Action Plan to Prevent and Combat Multidrug- and Extensively Drug-Resistant Tuberculosis in the WHO European Region, 2011-2015*. Geneva: World Health Organisation

16 WHO (2013) *Global Tuberculosis Report 2013*. Geneva: World Health Organisation

## POLITICAL COMMITMENT ON M/XDR-TB IN THE EUROPEAN REGION

Through the endorsement of the MAP, Ministers of Health and Governments from across the European Region made a political commitment towards a future free from M/XDR-TB. The MAP comprises seven areas of strategic intervention, including the need to scale up the medical and technical capacity of health systems, strengthen surveillance of M/XDR-TB, and prevent the development of M/XDR-TB cases.

The MAP contains certain areas of interventions and indicators that are particularly relevant to civil society such as the need to expand country capacity to scale up advocacy, partnership, policy guidance, and address the needs of special populations. These specific areas of interventions and indicators are hereinafter referred to as “community aspects of MAP”.<sup>17</sup> The remainder of this report will assess the progress that has been made towards achieving community aspects of MAP, with particular emphasis on high burden countries of the region.

## PROGRESS ON THE IMPLEMENTATION OF COMMUNITY ASPECTS OF MAP

**Our findings indicate that progress on the community aspects of MAP has been slow and that further action is necessary to reach the MAP’s targets by 2015. To date only one of the community aspects of MAP has been fully reached and progress towards the remaining community aspects of MAP is highly varied.** In this section we will explore the progress that has been made towards regional coordination among key stakeholders, the involvement of civil society in regional policy dialogue, as well as towards tools used for better informed and more inclusive policies.

### ▷ REGIONAL COORDINATION AMONG STAKEHOLDERS

Ensuring partnership and coordination between all stakeholders is paramount in effectively tackling TB at national and regional level.<sup>18</sup> In 2012, WHO Europe established the Regional Collaborating Committee on Tuberculosis Control and Care (RCC-TB) representing the only community aspect of the MAP that has been

<sup>17</sup> The areas of intervention evaluated for our research were: 6.4 Ensure partnership and coordination; 6.5 Involve ACSM/ civil society; 6.6 Safeguard ethics and human rights. Within these we evaluated the following indicators: 6.4.1. Regional multi-stakeholders coordination committee established and sustainably funded to assist in scaling up response to MDR-TB; 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 workplan; 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

<sup>18</sup> The Consolidated Action Plan to Prevent and Combat M/XDR-TB 2011-2015, chapter 6 “Expand country capacity to scale up the management of drug-resistant TB, including advocacy, partnership and policy guidance”

CIVIL SOCIETY CALL FOR AN IMPROVED RESPONSE TO M/XDR-TB AT THE INTERNATIONAL UNION AGAINST TUBERCULOSIS CONFERENCE - PARIS - 2013

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reached to date.<sup>19</sup> This regional multi-stakeholder platform aims to scale up funding for the M/XDR-TB response. The key objectives of the RCC-TB are to strengthen involvement and foster collaboration between national and international partners in TB and M/XDR-TB prevention, control, and care. The RCC-TB is envisaged as an “open-source” platform to facilitate and allow greater engagement with and among partners, stakeholders, and affected communities.

Activity of the RCC-TB has been the development of bilingual advocacy fact sheets on the involvement of civil society in TB care in the European Region, as well as on other issues including TB-HIV integration, and ambulatory care. These fact sheets have been developed with feedback from stakeholders, including civil society, academics, and researchers. The RCC-TB has potential to change the trajectory of M/XDR-TB in the European Region given its inclusion of stakeholders including donors, civil society groups, and technical organisations thus ensuring the pooling of expertise and improved coordination. The RCC-TB is an initiative that has the full backing of the WHO Europe leadership and is sustainably funded.

Another encouraging development at regional level is the systematic involvement of civil society representatives in NTP reviews throughout 2012, 2013 and 2014. This has allowed for the assessment of civil society and community involvement in TB programmes in several countries of the Region. Furthermore, WHO Europe has increasingly been supporting and facilitating the participation of patient representatives in regional TB events. These efforts contribute to raising not only political awareness and emphasising TB on the agenda of key stakeholders, but help patient supporters in capacity building and knowledge exchange. Since 2012, the WHO Technical Advisory Group (TAG) has a civil society representative; TAG provides a set of recommendations to WHO Regional Director and reviews the progress in implementation of recommendations. Since 2013, TAG also includes an ex-MDR-TB patient as a full member of their Committee.

### ▷ INVOLVEMENT OF CIVIL SOCIETY

While there has been clear regional progress towards the involvement of civil society in regional policy dialogue, this is not yet being fully replicated at national level. Only five of the countries surveyed have functioning national multi-stakeholder platforms. The remaining 13 priority countries either only have the idea of a partnership down on paper or have no functioning partnership at all. **This number currently falls well below the target of 18 high priority countries having a national TB platform or similar mechanism of coordination up and running with meaningful involvement of all stakeholders.**

Of the five countries that do have national partnerships – Republic of Moldova, Romania, Tajikistan, Turkey and Ukraine – there is representation of patients or patients’ organisations among the partnerships’ members. However, in certain countries key stakeholders such as HIV service organizations, people who use drugs (PWID) and former patients, have not always been included. In many countries, there are Country Coordinating Mechanisms (CCMs) that have been playing this platform role, but their scope is most often exclusively focused on Global Fund grants and processes, which may not reflect the full scope of the national TB response such as the obligations of the government and the contributions of other donors. In many countries CCMs unfortunately still do not include representatives of TB patients who have strong links with, and truly represent their constituency or of civil society actors who are working with populations most affected by TB. There is hope that this will begin to change with the Global Fund’s New Funding Model (NFM) that clearly lays out the need to include civil society in decision making on the CCM. By involving a broader set of constituencies, national partnerships can increase their leverage and benefit from a greater pool of expertise. **The establishment of inclusive national platforms should be a key focus for countries in the near future.**

<sup>19</sup> 6.4.1. Regional multi-stakeholders coordination committee established and sustainably funded to assist in scaling up response to MDR-TB

## PROGRESS ON THE IMPLEMENTATION OF COMMUNITY ASPECTS OF MAP

INDICATORS	NUMBER OF HIGH BURDEN COUNTRIES	
	Achieved the indicator	Did not achieve the indicator
Established a national TB partnership	5	13
Conducted KAP in the past 5 years	15	3
Conducted client satisfaction assessments in the past 5 years*	7	11
TB partnerships include TB patients	5	13
Governments financially support civil society	2	16
Use Patients’ Charter to safeguard ethics and human rights	2	16

### ACHIEVEMENT OF THE INDICATORS

Joint planning of advocacy, communication and social mobilization (ACSM) and MDR-TB activities took place		
Yes	No	Undetermined
8	7	3
There is an ACSM strategy		
Yes	No	Undetermined
12	2	4
Extent of funding of the ACSM strategy		
Fully funded	Not funded	Partially funded or undetermined
1	4	9
There is an ACSM work plan		
Yes	No	Undetermined
8	7	3
Extent of funding of the ACSM work plan		
Fully funded	Not funded	Partially funded or undetermined
0	3	9

\* 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.

## ▷ BETTER INFORMED AND MORE INCLUSIVE POLICIES

Conducting TB knowledge, attitude and practice (KAP) studies is critical as the information gathered can be used to improve services to best address the M/XDR-TB epidemic, indicating directions for priority action. The value of KAP studies lies in the fact that they can help identify the reasons behind patients' interrupting their treatment and explain what causes inappropriate or substandard treatment and care. Essentially, these studies are valuable in identifying knowledge, patterns of gaps, and cultural or behavioural beliefs that facilitate understanding and areas for action.<sup>20</sup>

Encouragingly, **77% of high priority countries in the EECA region have conducted KAP studies in the past five years.** The findings of these studies should provide a solid foundation for designing interventions and measuring impact. It is imperative that these KAP findings are made available to relevant stakeholders, including civil society, as a means of ensuring effective policy-making and in making steps to improve current activities so they have a greater impact in reaching those who are most in need.

**None of the countries assessed in our research have succeeded in having both a fully funded national advocacy, communication, and social mobilisation (ACSM) strategy or work plan.** Fully financed Advocacy strategies are central in ensuring that M/XDR-TB remains high on the national political agenda and that financing is increased and sustainable. Communication and Social Mobilisation strategies typically play a key role in improving case detection and treatment adherence by tackling the root causes of stigma and discrimination, and the gap in supporting these represents a missed opportunity. In response to the phasing out of international donors such as the Global Fund, the intention of having a target for fully funded ACSM strategies was to facilitate the necessary steps towards sustainability and to help support and build resilient communities.

Fully funding those strategies could have helped build civil society's ability to: hold government or international actors more accountable; increase political and financial will; address the persistence of social norms and attitudes that act as barriers to seeking treatment; communicate about what TB services and treatment are; address the persistence of stigma and discrimination and create inclusive TB programmes by involving key affected populations in decision making processes. Over the years, the ACSM concept is gradually being replaced by CSS: **Community Systems Strengthening (CSS).** **By financing CSS activities, countries will be promoting the sustainable development of informed, capable, and coordinated civil society.**<sup>21</sup> In doing so, civil society, particularly local community actors, will be more effective in their advocacy, communication to the public will be enhanced and social mobilisation amongst civil society with direct knowledge and experience of TB and other health issues is likely to improve. Importantly, CSS activities can be included and budgeted for in Global Fund concept notes.

A final but by no means less important tool is ensuring that countries are **using the Patients' Charter to safeguard human rights and ethics.** The responses from countries on the use of the Patients' Charter were either contradictory or individuals did not have the information. Only in Bulgaria and Estonia were there some reports of the use of the Patients' Charter that was difficult to fully confirm. Conflicting responses, in some cases from within the same country, on the use of the Patients' Charter is alarming as this indicates that these documents are not in widespread use across the region. Information about patients' rights can decrease stigmatisation, reduce obstacles in accessing diagnosis and treatment, address confidentiality issues, prevent informal or out of pocket payments, increase treatment adherence and completion, and ultimately will have a positive impact in lowering the number of TB deaths. Therefore governments should ensure that **the charter is appropriately translated and financing must be available in order to carry out effective communication strategies so that patients and health workers are fully aware of its existence and importance.** In doing so, treatment adherence and treatment success rates can improve. Important to note is that, similarly for ACSM activities, the financing of such work can come from the human rights module of the Global Fund concept note for those countries that are eligible.<sup>22</sup> The WHO routinely collects quantitative 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 comprehensively validated data was not available. Bulgaria and Estonia did not report dissemination and training on the use of the Patients' Charter. Even when validated, such dissemination and training do not yet ensure that the Patients' Charter is used to protect human rights and ensure ethics. In general, more detailed qualitative information is required in order to determine how well human rights and ethics are safeguarded in the European Region. Country support is crucial in making further progress in this area.

20 Ferreira Júnior, Sérgio, Oliveira, Helenice Bosco de, & Marin-Léon, Leticia. (2013). Knowledge, attitudes and practices on tuberculosis in prisons and public health services. *Revista Brasileira de Epidemiologia*, 16(1), 100-113. Retrieved October 03, 2014, from [http://www.scielo.br/scielo.php?script=sci\\_arttext&pid=S1415-790X2013000100100&lng=en](http://www.scielo.br/scielo.php?script=sci_arttext&pid=S1415-790X2013000100100&lng=en). 10.1590/S1415-790X2013000100010.

21 The Global Fund to Fight AIDS, TB and Malaria (2014) *Community Systems Strengthening Framework*. Global Fund: Geneva.

22 The Global Fund to Fight AIDS, TB and Malaria (2014) *Standard Concept Note Instructions: Investing for Impact Against HIV, TB and Malaria*. Global Fund: Geneva.

## CONCLUSIONS

1. Despite great progress at regional level with the establishment of mechanisms such as the Regional Collaborative Committee on TB, it is clear that **collaboration is still limited at a national level with only five of the countries surveyed reporting functioning national multi-stakeholder platforms.** Civil society is not yet systematically involved in national policy dialogue and exchange of information between governments and civil society and other stakeholders, including the private sector and academia, remains inadequate. **The establishment of national platforms that systematically involve civil society should be a key focus for countries in the near future.**
2. Encouragingly, more than three quarters of the countries use knowledge, attitude and practice (KAP) studies. However none of the countries have both a fully funded advocacy, communication and social mobilisation (ACSM) strategies and workplan. Applied in tandem with technical interventions, ACSM activities could have contributed to improving treatment outcomes for TB and M/XDR-TB in the European Region. **Countries must now ensure that Community Systems Strengthening activities are fully financed and implemented in order to ensure effective involvement of civil society in TB programmes.**
3. The use of the Patients' Charter has been reported in two high TB priority and high M/XDR-TB burden countries only; **national governments should do more to systematically ensure that patients are made aware of their rights and responsibilities and that adequate ethical procedures are being followed.**
4. Civil society projects in high priority and high burden countries are highly dependent on external funding, especially from the Global Fund. **National governments must be encouraged to work in a more inclusive manner and find ways to better support the work of civil society, especially to access vulnerable populations most affected by TB.**

PARTICIPATION OF A COMMUNITY REPRESENTATIVE ON WHO NTP REVIEW IN ARMENIA

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## RECOMMENDATIONS

### TO NATIONAL TB PROGRAMMES:

- Recognise civil society and affected communities as respected partners across all components of national TB programmes.
- Systematically consult, involve and empower civil society and affected communities in the development of National Strategic Plans.
- Include civil society and affected communities in the design and implementation of all TB control activities.
- Ensure civil society and affected communities are represented in all existing mechanisms of collaboration for better TB control, such as the Country Coordinating Mechanisms (CCM) and thus contribute to further improving and consolidating relationships with civil society.
- Provide civil society with the support needed to carry out core activities.

### TO THE NATIONAL GOVERNMENTS / MINISTRIES OF HEALTH:

- Urgently speed up the use social procurement schemes to provide civil society with the support needed to participate in the TB response, based on their unique knowledge of and links with key populations affected by TB.

### TO THE CCMS:

- Involve civil society, key affected populations and TB activists in country dialogues, in the development of National Strategic Plans, Concept Notes, and national sustainable financing plans, as outlined in the New Funding Model of the Global Fund.
- Ensure true and effective representation of civil society by feedback mechanism and plans of constituencies' engagement, transparent selection of CCM members from civil society 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.
- In Global Fund eligible countries, the Concept Note must budget for and include the following interventions:
  1. Localisation, translation, and dissemination of the Patient Charter as part of the human rights module.
  2. ACSM, TB networks and civil society strengthening as part of the community systems strengthening module.

### TO CIVIL SOCIETY:

Advocate for active participation in national TB platforms, and regional networks in order to:

- Share information and exchange knowledge.
- Coordinate and participate in policy dialogue.
- Step up advocacy for increasing domestic financing to TB response in line with commitments made in the MAP.
- Promote patients' rights and ethics by the use of an appropriately translated Patients' Charter.
- Reach out to NTPs and demonstrate the added value of civil society being involved in the design and implementation of TB interventions.
- Build sustainable relationships with other civil society actors (via national TB civil society platforms), especially those concerned with HIV and are engaged in other health issues or related sectors, such as gender and human rights and further improve and consolidate relationships with national TB programmes.

### TO WHO EUROPE:

- Continue to systematically involve and fully support at least one civil society actor and in support at least one community representative in each National TB Programme Review to evaluate progress on involvement of civil society in policy dialogue, service provision, and TB community systems strengthening components.
- Ensure that indicators related to the involvement of civil society are systematically assessed during National TB Programme Reviews and reported at the highest level of the governments.

### TO THE EU INSTITUTIONS:

- Demonstrate stronger regional political leadership on TB in the EU and the greater European region by adopting political and financing measures to ensure the sustainability of the TB response in the region.
- Play a more active role at country level via EU delegations on health issues including TB.
- Support local civil society actors in the European region to advocate for health rights and accountability.



GLOBAL HEALTH ADVOCATES FRANCE AND RESULTS UK  
ARE NGOS PART OF THE ACTION NETWORK  
AND HOST THE SECRETARIAT OF THE TB EUROPE COALITION

## THE TB EUROPE COALITION

is an informal advocacy network of civil society organisations and individuals that share a commitment to raising awareness of TB and to increasing the political will to control the diseases throughout the WHO Europe Region and worldwide.

## ACTION

is a global partnership of advocacy organizations working to influence policy and mobilize resources to fight diseases of poverty and improve equitable access to health services. ACTION was founded in 2004 as a partnership of civil society advocacy organizations with the shared mission of mobilizing new resources against tuberculosis (TB), a disease that kills one person every 20 seconds. ACTION partners work across five continents in both donor and high burden countries and advocate at the local, national, and global levels.



[WWW.TBCOALITION.EU](http://WWW.TBCOALITION.EU)

**ACTION**

[WWW.ACTION.ORG](http://WWW.ACTION.ORG)



[WWW.GHADVOCATES.EU](http://WWW.GHADVOCATES.EU)



[WWW.RESULTS.ORG.UK](http://WWW.RESULTS.ORG.UK)