civil society activity during the Soviet Union era means there are few historical precedents for NTP/CSO collaboration, resulting in a lack of awareness of the benefits collaboration can bring.

Fourth, **low involvement of TB patients, former patients and key affected populations in the development of TB programmes, awareness-raising and in TB care in general** is common in the Region. Stigma continues to prevent current and former patients from getting involved. This is starting to change, however, and all possible efforts should be made to encourage patient involvement in advocacy and TB-prevention activities. A general lack of understanding about the importance of adopting a patient-centred approach remains, despite patients having unique insights that can enhance the quality and safety of TB programmes. Increased patient participation in the design and implementation of the NTP would be extremely beneficial.

Addressing challenges that limit dialogue and coordination between CSOs and NTPs can strengthen the fight against TB in the Region. Providing accurate epidemiological information on the TB burden in key affected populations or being able to involve vulnerable communities in decision-making are just two of the ways in which the fight can be made more effective and sustainable when involving CSOs in TB programmes.

5. Recommendations

To ensure that civil society fully achieves its maximum potential in TB care and control, NTPs should:

- recognize 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;
- ensure CSOs and affected communities are represented in all existing mechanisms of collaboration for better TB control, such as country coordinating mechanisms; and
- provide CSOs and affected communities with the support needed to carry out their essential activities and coordination among themselves.

In parallel, CSOs and affected communities should:

- 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, especially those concerned with HIV or which focus on related issues such as gender and human rights;
- collaborate and coordinate their messaging to change government and NTP perceptions of fragmentation;
- engage in advocacy activities to leverage political commitment and increase financial resources for TB programmes; and
- seek additional donor and government funding to carry out their activities locally and internationally.

6. Methodology

Data used to compile this fact sheet were gathered through a survey on CSO/NTP collaboration prepared by the TB and MDR–TB programme of the WHO Regional Office for Europe and disseminated via WHO country programme officers. Twelve countries of the Region provided feedback. Face-to-face interviews were conducted with TB stakeholders from countries during the TB Europe Coalition Network meeting in Kiev, Ukraine on 21–25 April 2014.

Engaging civil society and affected communities in the fight against tuberculosis in the WHO European Region

1. Civil society and affected communities

Civil society, as defined by the World Bank, refers to the wide array of nongovernmental, not-for-profit and voluntary organizations that have a presence in public life, expressing the interests and values of members (or others) based on ethical, cultural, political, scientific, religious or philanthropic considerations. Civil society includes nongovernmental organizations (NGOs), community groups, faith-based organizations, foundations, advocacy groups and networks of people living with diseases.

Affected community refers to people living with, and affected by, tuberculosis (TB), including people at high risk of infection and those who bear a disproportionate impact burden. In this sense, affected communities include not only TB patients (and former patients), their families, friends and neighbours, but also people who are especially at risk of being infected: these are the so-called key affected populations and include health workers, prisoners, sex workers, migrants, people who inject drugs, the Roma community and people living with HIV.

2. Added value of civil society and affected communities in TB care and control

Civil society organizations (CSOs)[1] and affected communities are key players in responding to disease epidemics in countries and at regional and global levels. Being embedded in communities, CSOs are often well placed to take on operational roles in detection and patient support. They can also advocate for the interests of their members or the groups they represent and play an integral role in empowering key populations, helping reduce stigma and discrimination, promoting social and structural changes in the fight against TB and mobilizing resources, advocacy and policy dialogue. Affected communities possess unique knowledge on how their needs can best be addressed.

CSOs have in-depth knowledge of local contexts due to their work with key affected populations. This places them in a strong position to **raise awareness of TB among the general population** and **groups most affected by the disease.** For example, CSOs active in TB work can perform educational activities, raise awareness of TB symptoms and the availability of free TB care, and distribute information materials. Greater awareness and understanding of the disease not only contributes to a **reduction in TB-related stigma,** but also raises the profile of TB as a public health need in the country.

Stigma continues to be an issue in TB, with affected people commonly experiencing disease-associated discrimination or being shunned by their communities. Fear of discrimination can result in delays in seeking treatment and coinfection. CSOs can help combat discrimination by **accessing hard-to-reach communities and groups,** with community activists who carry out **social mobilization** activities becoming trusted by patients, communities and vulnerable groups. In Georgia and Tajikistan, for instance, religious and other community leaders are mobilizing to speak out about TB. Thanks to their influential position in society and the number of people they reach, these actors contribute greatly to increasing understanding of TB and facilitating early diagnosis.

Appropriately trained CSOs can also be service providers for vulnerable groups by, for instance, providing directly observed therapy services (DOTS) in ambulatory settings and ensuring treatment adherence by offering social and psychosocial support to TB patients and their families. Some CSOs in Kyrgyzstan actively support TB patients from vulnerable populations by providing outpatient treatment for injecting drug users (IDUs), a group from whom traditional structures

[1] *NGO and CSO have very similar meanings. Through custom and practice, NGO tends to refer to larger, possibly international not-for-profit organizations, while CSO usually denotes local and smaller organizations.*

typically are not equipped (or ready) to provide services.

As representatives of specific groups, **CSOs and affected communities can also be outspoken advocates on TB.** CSOs have the potential and moral obligation to demand action to solve problems people face at local and national levels. They have the ability to **leverage greater political commitment** on given issues and can help **mobilize additional financial and technical resources** to boost the fight against TB.
Affected communities, with their direct experience of people affected by TB and other diseases, are crucial to addressing the human and social dimension of TB. Their understanding of issues such as barriers in accessing TB care and obstacles to completing treatment can lead to better and more patient-friendly TB programmes being developed.

Greater involvement of affected communities and civil society in the design, monitoring and implementation of national TB programmes (NTPs) is essential for the development of comprehensive approaches that involve all actors and which may lead to better treatment solutions. The role of civil society and communities in TB care and control has also been acknowledged in key policy documents, such as the consolidated action plan to prevent and combat multidrug and extensively drug-resistant TB for 2011–2015, which was launched by the WHO Regional Office for Europe and endorsed alongside the WHO post-2015 TB strategy by all 53 countries of the WHO European Region on 15 September 2011.

3. Country examples of how civil society and community involvement have leveraged better results

The degree to which CSOs are officially involved in NTPs varies considerably from country to country. Reasons for variations differ, ranging from legislative challenges to a lack of CSOs working on TB.

Tajikistan is among the 15 high multidrug-resistant TB (MDR–TB) burden countries in the European Region. Thirty-seven CSOs work on TB projects in Tajikistan. Most began operating in the past 5–10 years and provide crucial services to patients and communities in prevention, case-finding and treatment adherence. Current CSO activities include: awareness-raising about TB symptoms and availability of free TB treatment; distribution of education and information materials; referral to TB facilities, DOTS, harm-reduction, treatment follow-up and psychosocial support services; and provision of incentives such as motivation packages containing food and transport vouchers. Their work is especially important due to Tajikistan's mountainous terrain, which makes it difficult to reach certain populations, and the fact that 47% of the population live in poverty (2009 figures).[2]

Tajik CSOs rely on small numbers of staff and about 3000 volunteers trained in outreach activities around health issues. Volunteers are carefully selected from the community and include teachers, community leaders and imams. After receiving TB training from the CSOs, they visit households in their communities and raise awareness of TB in schools, mosques and during religious ceremonies, including weddings.

CSOs are being increasingly recognised by the Government of Tajikistan as an indispensable actor in TB care and control and are now involved in discussions with the NTP. Greater local CSO involvement in TB control programmes and social support activities in recent years has contributed to an increase in case detection, ensured higher rates of treatment success and helped catalyse the shift to ambulatory treatment and care. Growing numbers of people are now being treated as outpatients: ambulatory care for MDR–TB patients grew from less than 10% of total TB treatments in 2009 to more than 45% in 2012.

The potentially transformative impact of CSOs' active involvement is further demonstrated in **Azerbaijan.** Over the past two decades, Azerbaijan has managed to achieve some of the best cure-rates for MDR–TB in prisons not only among former Soviet Union countries, but also worldwide. The Azerbaijani Ministry of Justice and the Main Medical Department have prioritized action to improve prisoners' health, such as implementing infection control measures, providing a continuous supply of certified medicines and facilitating early detection through rapid diagnostic tools and screening
National CSO involvement has complemented and strengthened Government efforts to improve MDR–TB detection and treatment in prisons. Saglamliga Xidmat, an Azerbaijani CSO, has been following-up former prisoners with MDR–TB since 2011 to address problems around treatment interruption following release. With support from the Main Medical Department and the Ministry of Justice, Saglamliga Xidmat has played a valuable role in providing psychosocial care and incentives to ensure former prisoners continue their treatment, with improvements in TB treatment adherence and success rates among newly released prisoners being demonstrated since their involvement in the prisons programme.[3] This example typifies what can be achieved through partnerships between NTPs and CSOs, particularly in addressing TB in vulnerable populations.

The effective role that CSOs and affected communities can play in addressing TB in vulnerable populations is further demonstrated in **Slovakia.** Here, community involvement has been central to addressing TB in the Roma community, which is typified by poorer health than is found in the general population. Under the Health Support Programme for the Disadvantaged Roma Community, community workers (Roma health assistants) were trained to provide (among other things) TB contact examinations, assess possible treatment side-effects and conduct daily interviews with patients. The programme is being implemented by the Ministry of Health in partnership with CSOs who support Roma communities. Community workers' involvement has led to treatment success rates among the adult Roma population increasing to 80%.3 It is unlikely this would have been achieved without community workers establishing closer links between the Roma community and the NTP.

The NTP in **Bulgaria** took a strategic decision in 2008 to work with CSOs to expand community awareness of TB and build patient support, especially in at-risk communities and groups. This intention featured in their applications to the Global Fund to Fight AIDS, TB and Malaria (GFATM). There are now 26 CSOs across Bulgaria contracted to the NTP. Few of these groups (which are mostly locally based) have experience of TB or even of health activity: some are focused on community welfare, others on HIV work and some on human rights. All, however, have the capacity to set up and run networks of community activists and volunteers.

Also relevant in the Bulgarian health care structure are the home-care nurses who work closely with CSOs. They are attached to local TB hospitals and spend part of their time with CSOs in local communities. The nurses provide a medical backbone to the NGOs' work: in return, the NGOs ensure the nurses have access to patients and communities (such as Roma and IDUs) who may be sceptical or suspicious about formal health services.

The system has fostered particularly harmonious relationships among CSOs, local TB services and the NTP. CSOs feel they are respected as equal partners in TB care and recognized for providing a service that formal health services cannot. Bulgaria has now achieved a significant drop in TB incidence, almost halving the rate over five years to 32 per 100 000 population in 2012.[4] The NTP and health professionals acknowledge that working with CSOs in a systematic way has been a major contributor to this success.

4. Challenges

Despite the transformative role they can play, CSOs working on TB in the European Region face important challenges. Although country contexts differ, the challenges are often similar.

First, the **number of CSOs working on TB remains very limited.** Reasons differ across countries, but predominant among them are: lack of domestic and international funding or incentives; legislative constraints, such as the need for special licences to provide health care services; and reluctance of HIV CSOs to expand their work to TB prevention and care due to fear of infection when working with TB patients. Consequently, TB CSOs in the Region are generally younger organizations that lack historical presence. A clear and formalized system to involve them in the work of NTPs needs to be developed in many countries.

Second, **a lack of funding,** which **impacts upon their sustainability,** is a major challenge for CSOs. CSOs in many countries are dependent on voluntary work or support from international donors, such as the United States Agency for International Development or the GFATM. When external funds are not available, CSOs lack the resources to sustain their TB-related activities and build capacity to collaborate with NTPs. This is the case in Georgia and Ukraine where, despite CSOs being involved in the preparation of NTP strategies, lack of resources to implement plans impede further collaboration between CSOs and the NTP.

Third, decision-makers in some countries often have a **negative view of CSOs.** They may see them as disorganised and unreliable work partners and perhaps view them as competitors, rather than allies, in defeating TB. This conception sometimes has its roots in **lack of coordination among civil society** actors, which represents a major challenge for TB and can hinder effective cooperation with governments and NTPs. A lack of

[2]Data. Tajikistan [online database] Washington (DC): World Bank; 2014 (data.worldbank.org/country/Tajikistan, accessed 29 September 2014).

[3]Best practices in prevention, control and care for drug-resistant tuberculosis. Copenhagen: WHO Regional Office for Europe; 2013 (www.euro.who.int/en/publications/abstracts/best-practices-in-prevention,-control-and-care-for-drug-resistant-tuberculosis, accessed 29 September 2014).

[4]Global tuberculosis report 2013. Geneva: World Health Organization; 2013 (www.who.int/tb/publications/global_report/en/, accessed 29 September 2014).