Question 3: *What types of social and behavioral (SBC) changes or outcomes are commonly sought within health system strengthening projects or interventions? How are SBC methods useful in creating behavior or norm change among government, private sector, and community health system actors? What are lessons learned regarding explicitly incorporating SBC approaches within HSS programs?*

Community engagement in TB care: building civil society partnerships for improved patient-centered services in Kyrgyzstan

Samantha Huffman, Ainura Ibraimova, Cholpon Ibraimova, Rakhat Cholurova, Aselia Abdurakhmanova, Ainura Kadyralieva
USAID Cure Tuberculosis Project, JSI

HEALTH SYSTEMS STRENGTHENING ACCELERATOR

Context

Kyrgyzstan is one of the 30 countries worldwide with the highest burden of multi-drug resistant tuberculosis. Drug-resistant tuberculosis (DR-TB) presents a significant challenge to the health system: the course of treatment for DR-TB is long and difficult for patients to adhere to, with many side effects; treatment success rates are low and many patients are lost-to-follow-up; there is ongoing transmission within the community from patients who go untreated or who interrupt or do not fully complete treatment; and pervasive stigma and discrimination in society complicates access to care. In addition, several hard-to-reach vulnerable groups, including people with a history of incarceration, homelessness, migration, or alcohol and substance misuse, are at higher risk of TB and treatment interruption due to behavioral and psychosocial issues, and often have less access to the health system. Successfully completing TB treatment in order to be cured requires prescription of effective treatment within a comprehensive patient-centered approach which addresses patients' psychosocial needs and provides support in a format convenient and accessible for patients.

Kyrgyzstan has a fragmented civil society landscape, with various civil society organizations (CSOs) providing services in the health and TB sphere under different donor-funded projects, with no formal system for engagement with the health system, varying levels of service quality, and no standardization of public health messages or services provided.

The USAID Cure Tuberculosis project, implemented by JSI in partnership with University Research Co., LLC (URC), engages CSOs by identifying their unique strengths, partnering with them to fill gaps in health care provision, and formalizing relationships with the health system. The project works through local CSOs to raise awareness of TB at the community level; help detect cases of TB and link them to care; and provide community-based treatment support to TB patients from vulnerable groups, in particular those at risk of treatment interruption or who are lost-to-follow-up or refuse treatment.

The project integrated a social and behavior change (SBC) approach from the inception stage to influence the behavior of TB patients to complete treatment; to encourage CSOs, family and community volunteers to provide community-based support to TB patients; and to enable health care workers at the primary health care (PHC) level to engage CSOs to support individual TB patients with specific psychosocial needs.

Activity Description

1) Integrating SBC approaches

The project began by conducting an SBC formative research study to better understand awareness of TB, barriers to TB testing and treatment, and stigma and discrimination among the general population, key priority groups, TB patients and health care workers. The findings of this formative research informed the development of a project SBC strategy, with key activities and tailored messages for each of the target groups. SBC project activities include the following:

- An extensive **awareness campaign** through mass media, social media, and community leaders to disseminate harmonized information about TB, urge people with symptoms to get tested, encourage community support of TB patients, and dispel the myths and misconceptions about TB that further stigma. The project also trains journalists to report on TB in an accurate and non-stigmatizing way, in order to ensure a uniform information environment on TB.
- Production and dissemination of short videos using a **behavioral journalism** approach, using real stories of people affected by TB, including patients, their families, health care workers and communities, to encourage positive behaviors around testing, treatment, and support of TB patients.
- **Trainings for CSOs and community leaders** and volunteers on using SBC approaches to work with key populations in order to detect TB cases among the community and provide community-based treatment support to TB patients. The project also works to strengthen the organizational capacity of CSOs involved in this work.
- Advocacy through Village Health Committees (VHCs) and Local Self-Government (LSG) entities to **mobilize resources** for TB patients in need within their communities.

2) Community engagement in TB care: establishing a role for civil society in TB case detection and case management

The project partnered with three local CSOs with specific strengths and attributes to work with key populations on changing behaviors:

- National Red Crescent Society, an organization with strong public health experience, to work with TB patients from various priority groups;
- TB People, a local CSO founded by people affected by TB and with strong peer ties to key high-risk groups, to work with formerly incarcerated people;
- Association of Village Health Committees, comprising a countrywide network of VHCs, to work at the grassroots level in rural communities.

To facilitate their work, the project developed tools to involve CSOs in active TB case finding among risk groups, including screening algorithms and questionnaires. Project CSOs conduct **screening among priority groups** in order to detect people with symptoms of TB and refer them for testing at PHC facilities.

The project strengthened and expanded a TB case management approach, which utilizes a multi-disciplinary team in charge of monitoring patients' treatment at the PHC level, including TB doctors, family doctors, nurses, and other specialists as needed. Through this approach, health care workers **assess TB patients to identify any psychosocial needs and link them to CSOs** that can provide community-based treatment support to help them complete treatment. As part of TB case management trainings conducted for PHC health care workers (HCWs), the project further developed an SBC module to train HCWs on the findings of the SBC research on patient barriers to testing and treatment, stigma and gender issues in order to improve HCW counselling and help HCWs better understand patients' psychosocial needs and identify appropriate sources of support. The TB case management training curriculum, along with the SBC module, was approved by the Kyrgyz State Medical Institute of Post-Graduate Training & Continuous Education.

The project also developed algorithms for CSOs to support TB patients at risk of treatment interruption to remain on treatment, and patients lost-to-follow-up or refusing treatment to return to treatment. The **social support package** provided by CSOs includes: community-based treatment support, psychosocial counselling, patient support groups, and food and hygiene packages for those most in need.

3) Formalizing linkages between the health system and civil society

In addition to developing the tools and algorithms described above, the project worked with the National TB Program and Ministry of Health (MOH) to develop and implement a series of decrees establishing a TB case management approach and tools, with an algorithm to engage CSOs in TB care:

- The project built on previous MOH Decrees on TB case management and expanded implementation countrywide, and helped develop a MOH Decree on TB case management standards. These decrees establish multi-disciplinary case management teams and allow for involving CSOs and/or community-based treatment supporters to provide psychosocial support to TB patients as members of the case management team, with specific responsibilities including monitoring of adverse drug reactions.
- MOH Decree on public procurement of social services approves a medical and social services package for TB patients to be provided by CSOs, allowing the MOH to contract CSOs directly.

In addition, the project played a leading role in the development of the new National TB Strategy, **Tuberculosis-VI (2023-2026)**, which for the first time includes SBC approaches. The national action plan includes an SBC strategy to improve testing, treatment, prevention and stigma and discrimination, and allows for involving CSOs in awareness-raising, case detection, treatment, and prevention activities.

Activity Impact

- By integrating SBC approaches throughout the project and fostering community engagement in TB care, the project has improved the **organizational capacity of CSOs and community entities** to participate in TB care.
- The project has improved **cross-sectoral coordination** by establishing formal mechanisms through which the health system can engage CSOs to provide support to TB patients in need.
- Through this approach, the project has improved **service delivery** by providing tailored psychosocial support to patients in need for higher quality patient-centered care.
- The project expanded **local financing** for TB care by engaging Local Self-Government entities – with previously limited involvement in TB care – to help support TB patients within their communities and mobilize additional resources for social support. Project training on advocacy and resource mobilization for Village Health Committees and Local Self-Government has built the capacity of these entities to generate additional resources independently going forward.

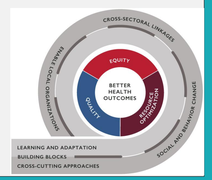
Overall, these approaches together contribute to all health system strengthening components of:

- **improved equity** of health services by improving access to services for hard-to-reach vulnerable groups,
- **improved quality of care** by emphasizing tailored, patient-centered care and quality standards for service provision, and
- **improved resource optimization**, by leveraging the capacity, access and reach of CSOs to peer vulnerable groups to link them to care; the close access of family and community members to provide treatment support to TB patients; and the capacity of alternative entities (such as VHCs and LSGs) to mobilize financial resources for TB patients.

Thanks to project advocacy, the approach of community engagement in TB care has been **institutionalized** through Ministry of Health decrees, mechanisms, and service standards, and the incorporation of SBC approaches and community engagement into the national TB strategy allows for **sustainability** of this approach beyond the end of the project.

PHC family doctor examines an elderly TB patient, Chui region

TB doctor and National Red Crescent Society nurse review a patient's file together, Talas region



Evidence

Awareness-raising and TB case detection

- Over the first three years of the project, the project trained **over 30,500 community leaders** on TB and SBC approaches.
- In turn, project CSOs and community leaders have reached **over 1.3 million people** through direct awareness-raising activities at the community level. Mass media and social media campaigns have reached much larger numbers of people through regular information and World TB Day programming.
- Over the first three years, CSOs have helped to screen 1,353 people for TB at the community level. Among people screened, 235 people were identified with symptoms suggestive of TB and referred to PHC facilities for testing; 207 of those underwent testing for TB. In total, **22 new cases of TB** were diagnosed thanks to CSO efforts (almost 10% of presumptive cases, in line with case detection standards) and 100% of those diagnosed with TB were initiated on treatment.

TB case management and patient support

- Over the first three years of the project, **2,645 health care workers** at the PHC level were trained on TB case management, including involvement of community-based treatment supporters in TB care. Among those, 2,461 received enhanced training on SBC aspects of TB care through the SBC module.
- **Almost 1,000 TB patients** (999) have received social support through CSOs, with 90% achieving improved treatment adherence. To date, 531 of these patients (53%) have completed treatment, 346 (35%) are still on treatment with strong adherence thanks to CSO support, and 18 (2%) are continuing treatment at PHC facilities without further need for CSO support owing to improved adherence. Ten percent are no longer part of the social support program for various reasons (Figure 1).
- In total, **47 patients** were brought back to care: 39 patients who were lost-to-follow-up were located by CSOs and returned to treatment and 8 patients who had refused treatment were persuaded to begin treatment.
- A nationwide Quality of TB Services Assessment (QTSA) conducted in 2021 found that community-based treatment supporters (family members and community health workers) are able to supervise treatment for TB patients **more regularly and frequently** (more days per week on average) than facility-based health workers (Figure 2). This data demonstrates the value of community-based support in providing better patient-centered care.

Figure 1. Support to TB patients through CSOs (999 patients)

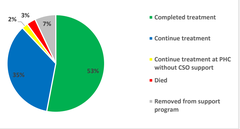
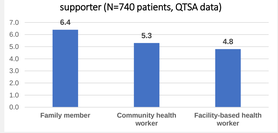


Figure 2. Average number of days per week treatment observed by type of treatment supporter (N=740 patients, QTSA data)



Facilitators

- Political will of the National TB Program and Ministry of Health to adopt innovative patient-centered TB case management approaches and further institutionalize them.
- Strong and effective partnership with the National TB Program as the main stakeholder in TB care, with growing interest in strengthening the coordination of CSO activities in community-based support to improve TB outcomes.
- Existing local CSOs with strong peer ties to priority groups and experience working in TB.
- USAID and other donor investments in working with CSOs under past projects and improving their capacity and experience.
- The project's strong partnership with the National TB Program and Republican Health Promotion Center from the inception phase, including their participation in the SBC formative research and development of the SBC strategy, were instrumental in helping to adopt SBC approaches at the national level through the National TB Strategy.

Challenges

The project faced challenges in working with patients from vulnerable groups (with issues of alcohol/substance misuse, incarceration, homelessness, etc.), including behavioral issues which complicate treatment adherence, lack of legal documents, frequent change of residence, and external migration. By working with CSOs, the Project was able to leverage their strong ties with these groups within their peer networks to help patients on an individual basis with other ad hoc needs, including legal support.

During treatment, many patients lose their jobs or are forced to quit work and thus face additional financial difficulties; therefore, additional sources of financial support, such as through LSGs, are very important to help patients continue treatment.

National Red Crescent Society volunteer brings food and hygiene packages to TB patients with mobility issues

Village Health Committee members provide information on TB at an informal meeting with fellow villagers

Lessons Learned

CSOs are well-positioned to work within communities and with vulnerable groups owing to the trust and access they enjoy and their understanding of the unique challenges faced by these populations. However, there is a need to develop uniform messages, standards for service provision, and formal mechanisms of engagement with the health system to ensure consistent provision of high-quality care.

In this way, CSOs can be an effective partner to the health system in helping to detect undiagnosed TB cases at the community level, locate patients who have fallen out of the health system's reach, and support patients with challenging circumstances to complete treatment. In tandem with improving the capacity of CSOs and community entities to conduct this important work, it is essential to influence health care workers to understand the value and potential of engaging community-based actors in TB care and utilizing SBC approaches to improve quality of care.

A patient with DR-TB receives his daily drugs from a local PHC health worker in Chui region

National Red Crescent Society nurse tells a migrant family member about TB

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