

The key asks of civil society and community organizations of 11 countries who are engaged in the Tuberculosis Regional Eastern European and Central Asian Project (TB-REP)



TB REP



Alliance
for Public Health



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We, the representatives of the civil society and community organizations in the Eastern Europe and Central Asia who are engaged in promoting people-centered model of TB care¹, in preparation for the UN General Assembly high-level meeting on ending tuberculosis (TB), reaffirm our commitment to ending the global TB epidemic, recognizing the key role of civil society as a partner in ending TB. We call on all Heads of State or Government to attend the High-Level Meeting and to commit²:

1. REACH ALL PEOPLE BY CLOSING THE GAPS ON TB DIAGNOSIS, TREATMENT AND PREVENTION³

- Acknowledge the indispensable role of the civil society and community organizations as local providers of people-centered care services, and increase commitment to provide them with the support;
- Make every effort to ensure that every facility and provider who are part of TB response are able to start treatment as soon as possible, as any delay in initiating treatment increases the chances of further transmission and loss to follow-up;
- Collect data on the effectiveness of case finding strategies, ensure outreach to all key population groups and people at higher risk and lower access to care, and regularly review of the case finding strategy at the country level to make sure that no one is left behind⁴;
- Ensure the transition to quality outpatient care, which is the closest to the needs of people, except for cases that require hospitalization. Social support for the people on ambulatory treatment should become an integral part of the provision of medical services.

2. TRANSFORM THE TB RESPONSE TO BE EQUITABLE, RIGHTS-BASED AND PEOPLE-CENTERED⁵

- Including the new model of TB care concept in the overall health system reform agenda and implement it as fast as possible;
- Overcome stigma and discrimination against people who have suffered or are suffering from tuberculosis, refuting common myths about the infectiousness of patients regardless of the stage of their treatment and the need for hospitalization for all TB patients; support implementation of the systematic stigma index assessment towards the people with TB; carry out regular assessment of all regulatory documents to ensure their compliance with the human rights approach;
- Ensure that key strategic information on major structural barriers affecting people care seeking behavior is collected through the existing tools on collecting evidence on barriers to finding people with TB who are missed by national programs and experience delayed access to care, in order to further remove the barriers and ensure timely and equal access to TB treatment and care;
- Ensure support for TB patients at all stages of treatment through social support for TB patients and their families; psychological support, counseling, and information; providing material support for adherence to treatment and preventing extremely high costs associated with the disease and the loss of income. Particularly, the costs reimbursement should include the coverage of expenditures for food, transportation and work loss because of tuberculosis;
- Support the design and implementation of the people-centred model of TB care in the context of the broader health and social systems, with special attention to service integration with other programmes including, but not limited to, HIV/AIDS, diabetes, hepatitis and other non-communicable diseases, maternal and child health and mental health and addiction services;

¹ WHO Regional Office for Europe (2017). A people-centred model of TB care: Blueprint for EECA countries that has been developed as part of the Tuberculosis Regional Eastern European and Central Asian Project

² Document reflects the position of the representatives of the civil society TB-REP partners, as from the meeting on June 20-21, 2018 Istanbul

³ Headlines 1-5 adopted from Key Asks from TB Stakeholders and Communities. United to End TB: an Urgent Global Response to a Global Epidemic

⁴ For example, with the use of Data for Action for TB Key, Vulnerable and Underserved Populations (STOP TB Partnership).

⁵ Taking into account the information provided in the brochure TB Europe Coalition Moving to People-Centered Care: Achieving Better TB outcomes"

- Promote implementation of the so-called “treatment enablers” - DOT home visits, including those with involvement of civil society and community organizations staff; supporting wide implementation of digital communication (text messages, calls) on medical issues; implement digital DOT models.

3. ACCELERATE DEVELOPMENT OF ESSENTIAL NEW TOOLS⁶ TO END TB

- Commit to increase investments for the research and development of new effective, safe, suitable and affordable TB tools and technologies;
- Ensure engagement of the TB affected communities in the processes of research and innovation for TB health technologies;
- Support reduction of terms for implementation of new technologies and registration of the new medicines, while ensuring their safety;
- Commit to promote registration and use of child-friendly TB formulations;
- Commit to increase investments towards expansion of treatment options for people who have TB through rolling out latest medications that are safe to use such as Bedaquiline and Delamanid, as well availability of GeneXpert machines in all clinics and point of care facilities;⁷
- Make sure that the benefits of scientific innovation are equitably accessible to all, as quickly as possible and intellectual property rights do not represent a barrier to rapid price decreases to make the new products accessible and affordable to all countries most affected TB;
- Scale up availability of testing and access to treatment for latent TB infection, particularly in high-burden countries.

4. INVEST THE FUNDS NECESSARY TO END TB

- Ensure that any plan to reduce hospitalization provides effective mechanisms to maintain the funding for TB and reallocate saved funds to higher quality clinical and patient support services, as well as newer diagnostics and treatment options, including putting in place transparent mechanisms for monitoring of the effectiveness of the use of reallocated financing;
- Link provider payment mechanisms to performance improvements based on the new model of TB care, including quality and integration;
- Support the development of a social contracting mechanism for civil society and community-based organizations or other non-health professional-based organizations to provide psychosocial support, active case-finding and treatment administration;
- Promote partnership between governmental and private sector, including allocation of specific funds for supporting people under TB treatment.

5. COMMIT TO DECISIVE AND ACCOUNTABLE GLOBAL LEADERSHIP, INCLUDING REGULAR UN REPORTING AND REVIEW

- Conduct rapid assessments or situation analysis of the current status of the TB model of care (TB services delivery in ambulatory and hospital care, including current national treatment guidance and policies) at the country level to inform development of a new model or improvement of the existing one using the detailed guidelines in the Blueprint of the people-centered model of TB care⁸;
- Ensure the involvement of all stakeholders and sectors to institutionalize the recommended health policy changes. Professional and governmental silos need to be broken by nurturing and supporting “boundary spanners” and through investment in developing leaders who are prepared to challenge the status quo bias of many key players;
- Ensure that the shift to people-centered care is tracked by using appropriate indicators showing higher quality services provided to people affected by TB (i.e. introducing an indicator on patients receiving patient support (social, material, psychological);

⁶ Tools and Medicines

⁷ Adopted from Key Asks for the UN High-level Meeting on Tuberculosis on behalf of Affected Communities and Civil Society, and endorsed by STOP TB Partnership

⁸ http://www.euro.who.int/__data/assets/pdf_file/0004/342373/TB_Content_WHO_PRO_eng_final.pdf?ua=1

- Ensure that people, affected by TB participate in the country coordinating bodies responsible for decision-making on how the TB care should be organized;
- Support implementation of the effective system of the epidemiological monitoring at the country level as well as ensuring the linkages between the systems at the regional level;
- Strengthen the existing accountability mechanisms, including UN system mechanisms for tracking global, regional and national progress on TB and implementation of the TB UN HLM Political declaration; commit to inclusion of the civil society in all accountability processes. Establish an independent accountability framework at the global, regional and national levels to monitor commitments from the Political declaration.