KEY POPULATIONS BRIEF

RURAL POPULATIONS

Stop TB Partnership

Global statistics indicate that the TB burden is more acute in urban areas. However, in countries where large portions of the population are rurally located and reside in extreme poverty, TB is dominant among rural dwellers. Poverty and limited access to health facilities and health workers significantly diminish the ability of people with TB who reside in rural areas to obtain timely diagnosis and treatment. Stigma and widespread lack of knowledge about TB are also more common in rural communities. Multiple strategies to overcome these barriers exist and should be implemented at scale. This guide provides an outline of the specific challenges faced by rural dwellers and how these challenges can be addressed.

Global Plan to End TB and key populations

The Global Plan to End TB outlines the following targets to be achieved by 2020, or 2025 at the latest. The Plan refers to people who are vulnerable, underserved or at risk as TB "key populations" and provides models for investment packages that will enable different countries to achieve the 90-(90)-90 targets. The Plan also suggests that all countries:

Reach at least

90%

OF ALL PEOPLE WITH TB

and place all of them on appropriate therapy—first-line, second-line and preventive therapy as required

As a part of this approach, reach at least

(90)%

OF THE KEY POPULATIONS

the most vulnerable, underserved, at-risk populations

Achieve at least

90%

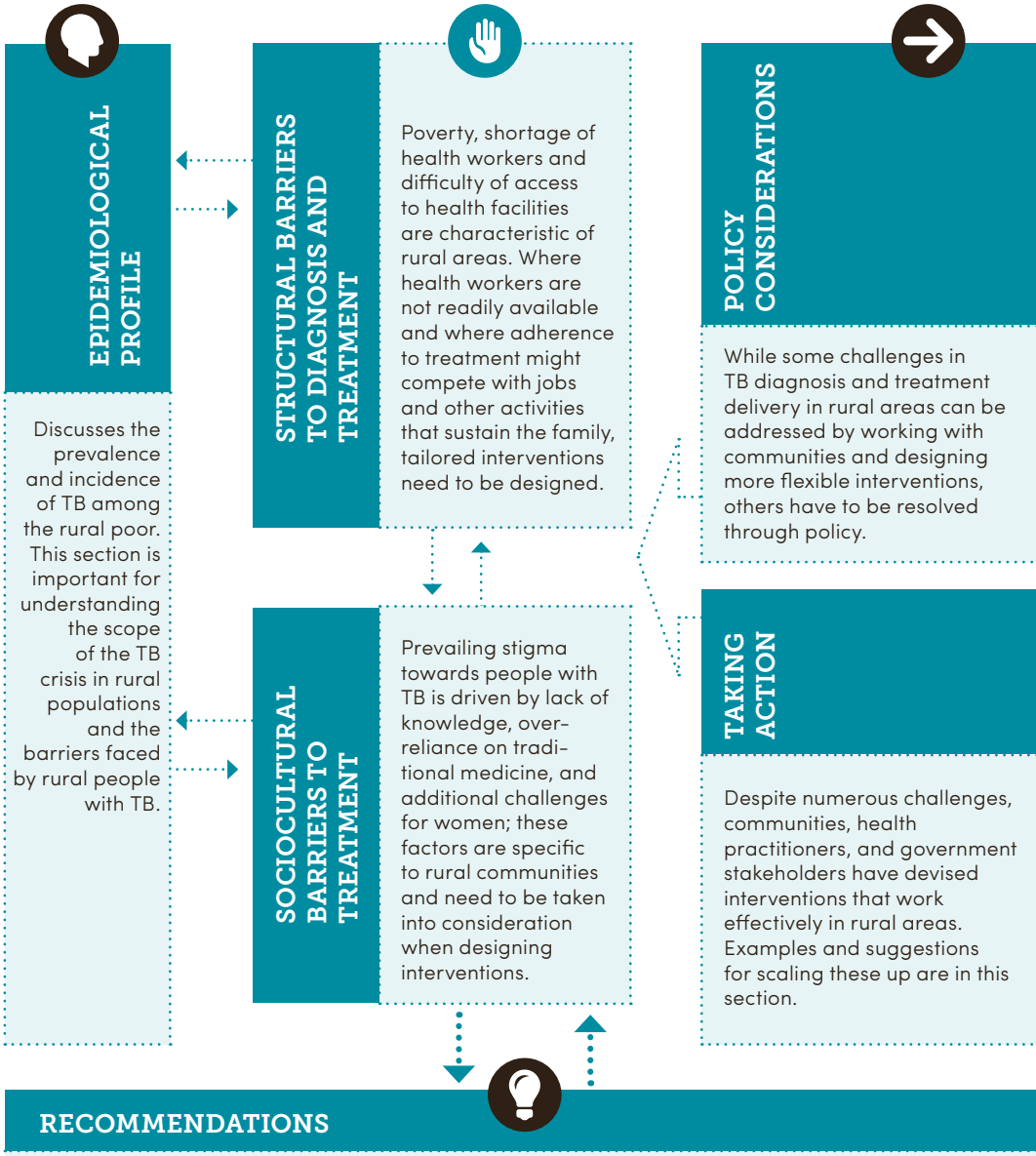
TREATMENT SUCCESS

for all people diagnosed with TB through affordable treatment services, adherence to complete and correct treatment, and social support.

- Identify their key populations at national and subnational levels according to estimates of the risks faced, population size, and particular barriers, including human rights and gender-related barriers, to accessing TB care;
- Set an operational target of reaching at least 90% of people in key populations through improved access to services, rights-based systematic screening where required, and new case finding methods, and providing effective and affordable treatment to all people in need;
- Report on their progress with respect to TB using data that are disaggregated by key population;
- Ensure the active participation of key populations in the development and delivery of services and the provision of TB care in safe and respectful environments.

This Guide utilizes the above recommendations to discuss structural barriers to access, as well as local-level solutions for rural populations with TB.

What's in this guide?



Epidemiological profile

Globally, the prevalence of TB is considerably higher in urban areas than in rural areas *(1)*. However, in some countries, these statistics are reversed, with individuals residing in rural areas at much higher risk of contracting TB disease. For example, in China, where 80% of the population is rurally located, the prevalence of active pulmonary TB in rural areas is 1.8 times higher than in urban areas *(2)*. Similarly, in other developing countries where large portions of the population are rurally located, TB incidence in rural areas is greater than or equal to that in large urban locales *(3,4)*. In other settings where overall prevalence and incidence are higher in urban areas, some rural provinces might experience heavier TB burdens but receive less attention from donors and policy makers *(5)*.

Delays in correct diagnosis and the initiation of effective treatment increase TB morbidity and mortality, risk of transmission, and the development of drug-resistant forms of TB in rural communities. Access to TB diagnosis and treatment is significantly delayed for people with TB who reside in rural areas *(6)*. These delays and the lower treatment adherence and completion rates among rural dwellers are due to a variety of factors: individual-level factors, such as trust in alternative medicine, and structural factors and other issues, such as the inability to get to a facility because of the distance, lack of, as well as cost, of transportation, cost of treatment, having to choose between work and treatment, distrust of providers, and so on *(7–9)*. Considering these challenges, along with the often lower socioeconomic status of rural versus urban residents, the scarcity of health facilities, and the prevailing stigma of TB disease in rural settings, TB poses a significant risk for rural dwellers.

Structural barriers to diagnosis and treatment

Poverty

In 2011, the International Fund for Agricultural Development reported that 70% of the world's 1.4 billion extremely poor live in rural areas *(10)*. The conditions of extreme poverty in which the majority of rural TB patients live can influence not only the initiation of diagnosis and treatment and the ability to continue on treatment once diagnosed, but also such important aspects of treatment as access to nutrition and sanitation. Rural residents who might be employed as seasonal labourers or take other jobs far from home might be especially disadvantaged, since their options for diagnostics and treatment are severely limited by their mobility in search of income.

Availability of health workers and health facilities

According to WHO, nearly 50% of the world's population lives in rural areas, but less than 38% of nurses and less than 25% of physicians work in these settings *(11)*. This situation is more pronounced in the 57 countries that WHO has identified as having an absolute shortage of health workers *(11)*. Of the 22 countries in the world with the highest TB burden, 15 are among those experiencing dire health worker shortages.[1] The devastating lack of health workers in rural areas is a problem that is global in scale, particularly impacting already impoverished rural districts in developing countries *(12,13)*. Study participants in multiple settings have reported that, where accessible, those health clinics capable of providing TB care operate with limited and unpredictable opening hours, long waiting times, and frequent provider absenteeism *(9)*. Some studies have also shown that, when faced with the task of delivering supportive treatment to their catchment area, overstretched clinic staff sometimes forgo these responsibilities due to an overwhelming patient burden or other constraints *(14)*. Rural people with TB who have more complicated diagnoses or multidrug-resistant (MDR) strains of TB might not be able to access health facilities where they live; therefore, they must undertake significant hardships to access diagnosis, treatment and care services in urban and peri-urban areas. In addition, rural clinics might experience medication stock outs or shortages more often than those located in urban settings *(15–17)*.

1 These countries are: Afghanistan, Bangladesh, Cambodia, DR Congo, Ethiopia, India, Indonesia, Kenya, Mozambique, Myanmar, Nigeria, Pakistan, Uganda, United Republic of Tanzania, and Zimbabwe.

Distance to health facilities

In settings where there is diminished availability of health care facilities, the main structural barrier to many rural people with TB first obtaining and then adhering to treatment is the distance they must travel in order to access diagnostics and treatment. This distance can cause significant delays in diagnosis and treatment initiation, and hinder the ability of people with TB to adhere to treatment *(9)*. Rurally located people with TB might be required to travel daily to a health facility site in order to receive their treatment, regardless of how sick they are or their work schedule. This leaves them vulnerable to worse treatment outcomes and higher rates of loss to follow-up *(18)*. In addition, longer distances imply higher costs of travel, which already disadvantaged rural residents might not be able to afford. In rural areas, for many people with TB, the need to attend daily treatment conflicts with the more urgent need to earn a living *(9)*. Recent findings regarding the efficacy and effectiveness of self-administered treatment in remote areas have been encouraging, and such treatment should be considered for further scale-up in rural areas around the world *(19)*.

Cost of treatment

The scarcity of health facilities and health workers, accompanied by the general decline of rural health systems, often results in corruption and dependence on informal or other additional payments in such settings *(20)*. Efforts to minimize the costs of TB medications for patients have been ongoing. But even where countries have adopted free TB diagnostics and treatment policies, other activities associated with treatment – such as medical examinations (e.g., chest X-rays), additional medications prescribed by doctors to accompany TB drugs, hospital stays, and time taken off work – often imply a catastrophic cost for patients *(21)*. This is especially true in rural areas, where health workers might be encouraged to supplement their income with extra fees *(22,23)*. Studies from different regions have reported patients spending up to 40% of their annual income on TB-related health services *(24–26)*. In addition, rural people with TB might not be aware of national-level policies related to TB treatment and are therefore unable to demand the services to which they are entitled.

Sociocultural barriers to treatment

Alternative health care and services

Studies across health conditions have found the reliance on traditional and alternative medicine to be generally more common in rural areas. Individuals experiencing TB symptoms in rural areas might be more likely to initially visit a traditional healer or a herbalist, thereby delaying access to formal diagnosis and treatment initiation *(27–30)*. Traditional healers and alternative health care providers might also be more accessible in terms of distance travelled, cost, familiarity, trustworthiness and rapport *(31)*. For example, in sub-Saharan Africa the ratio of traditional healers to the population is 1:500, whereas the doctor to population ratio is 1:40,000. As such, the benefits of involving traditional healers in providing formal TB treatment cannot be underestimated *(32)*. Evidence has shown that giving people with TB the option to have supportive TB treatment delivered by traditional healers can positively influence both treatment outcomes and other aspects of the treatment experience *(33)*.

Stigma and discrimination

The association of TB disease with poverty and the fear of resistant forms of TB continue to fuel stigma and discrimination, which in turn negatively impact treatment-seeking behaviours and treatment adherence. Moreover, such stigma can have serious socioeconomic implications, particularly for women *(34,35)*. Rural residents experience higher levels of stigma and discrimination than their counterparts in urban settings and have less knowledge regarding modes of transmission, diagnosis and treatment, which may in turn contribute to these phenomena *(34,36)*. In rural settings with heightened prevalence of HIV, TB might have additional stigma as a marker for HIV and behaviours that might be stigmatized. In close-knit rural communities, TB stigma might prevent patients from accepting supervised treatment in their homes, where visits from health workers would be immediately noticed by the community *(34,37,38)*. Self-stigmatization and self-discrimination might also contribute to the further social exclusion of people with TB. For example, despite being told repeatedly that they were no longer infectious after the first two weeks of treatment, people with TB in Nepal exhibited signs of self-stigma for the entire duration of their treatment *(35)*. Some research on the experiences of people with TB has also reported discrimination from health workers and clinic staff, or activities by health workers that propagate stigma, such as excessive cautioning and treating clinic door mats with chemicals, among others *(35,39)*.

Gender

Women's health is often deprioritized within families, where preference is given to the health of children and men, who are also considered the primary earners *(40)*. Women experience longer delays in obtaining diagnosis for TB in multiple settings *(6)*, which might be explained by their traditional roles within the family and caretaking responsibilities. In many locales, due to social and cultural constraints, rural women have difficulty travelling to health facilities; they either need a male escort or money to which they have limited access *(18,41,42)*. Thus, the concerns associated with the distance to a health facility are even more central for women. In multiple settings, women have reported fears that a TB diagnosis could limit their options for marriage or impact their relationships with their current spouse and relatives, thus putting them at risk for further social stigma and economic disadvantage *(42)*. Women from India, Uganda, and many other locales have reported being abandoned by their husbands and excommunicated by their families when they were diagnosed with TB *(42–44)*. Other reports also indicate that women diagnosed with or even those who have been treated for TB are thought to be unsuitable for marriage or motherhood *(45)*. In rural settings, where neighbours and families might be more closely acquainted, these attitudes are tragic for women, as they are ostracized by their families and communities and have no place to turn to for support. Studies in rural settings have found that men demonstrate greater knowledge about TB than women, which may also influence both health-seeking behaviour and treatment adherence *(42)*. In some countries, rural women have demonstrated greater awareness of TB and/or better treatment seeking and adherence; in cases where rural women were closely familiar with the health care system and trusted providers (through scale-up and encouraged antenatal care visits, etc.), they were more likely to present for diagnosis of TB earlier *(27)*.

Indigenous status

It is important to note that a large proportion of the world's indigenous populations are rurally located and that globally these populations are disproportionately affected by infectious and other disease, including TB *(46)*. Where indigenous populations are additionally marginalized and remotely located, their access to appropriate TB treatment and care might be even more limited than that of the general rural populations. Existing data show a much higher prevalence of TB among indigenous groups in Australia, Canada and the United States *(47)*. A recent review of global evidence found similar trends in other countries; for example, in the indigenous people of the Brazilian Amazon, TB incidence is 20 times higher than the incidence in Brazil's general population, and in certain tribal groups of India, TB prevalence was found to be over 100 times greater than the national average *(47)*. Research on TB among indigenous people is also not readily available, which could further hamper adequate service delivery to this group.

Considerations for laws and policies

Rural-to-urban migrant status

There is ample evidence that rural-to-urban migration is common across settings *(48)*; thus, concerns about ensuring that rural-to-urban migrants obtain relevant standards of care for TB are universal. In countries like China, studies have revealed higher out-of-pocket costs, lower knowledge about reimbursement policies, and lack of health insurance among rural-to-urban migrants, as well as job loss associated with TB diagnosis and the need to borrow money from family and friends in order to undergo treatment *(49,50)*. Better policies thus are needed to include rural-to-urban migrants in nationally funded health insurance schemes and to ensure employer nondiscrimination for these and other vulnerable populations. The constraints affecting TB prevention and treatment access in rural-to-urban migration are covered in more detail in the STOP TB Mini-Guide on Migrants.

Persistent discrimination in employment and inheritance laws

Despite multiple statutes prohibiting health-based discrimination in both international *(51)* and most national legal frameworks (where national TB laws, for example *(52)*, specifically state that people with TB will be secured their employment while undergoing treatment), people with TB still experience discrimination in employment and maintain the fear of being fired or laid off from their jobs if their condition is discovered *(34,35)*. This might especially impact the rural poor who maintain unsteady or seasonal employment and/or are employed under conditions that are not in their favour. In addition, laws or practices prohibiting women from inheriting land in many countries *(53)* impact widows of people with TB and women with TB in rural communities where these practices are more likely to be maintained. These practices and policies need to be put under close scrutiny in order to prevent rural workers and women from being further discriminated against.

Rural allowance for retention of workers

In some countries, governments have begun implementing a system of incentives to increase doctor and nurse retention in rural and hard-to-reach areas *(54,55)*. While these interventions have been effective at increasing recruitment in some areas, these interventions have also caused dissatisfaction among junior staff, since pay increases are designated for only higher level staff, among other challenges *(55,56)*. Thus, rural allowance systems need to be closely monitored to ensure their long-term impact and sustainability.

Taking action

Changing treatment modalities – engaging community, alternative health service providers and family

- India's project Axshya (TB Free) engages thousands of volunteers from local grassroots nongovernmental organizations (NGOs) to conduct SAMVAD (dialogue in Hindi). The volunteers use low-literacy materials to discuss TB in communities in order to lower stigma, identify symptoms, and provide referrals to the nearest diagnostic facility. SAMVAD volunteers also arrange for sputum testing of those who are not able to make it to the facility, navigate diagnosis and treatment procedures, and serve as supportive treatment providers.

- In other settings, similar interventions have been led by community health workers (also known under different titles, such as health extension workers, rural health workers, etc.). These are trained individuals who do not have medical training, but who are respected and trusted by the community and can serve as case workers for multiple health conditions, including TB. Community health worker models have demonstrated success in rural communities from Ethiopia to Haiti, and are cost–effective and efficient to implement *(57)*. In Mexico and other Latin American countries, community health workers, also known as promotoras (es), mix traditional and formal medicine to treat and support patients with a variety of conditions, including TB *(58)*.

- Collaboration with traditional and alternative healers in rural communities in multiple countries has demonstrated positive results for TB treatment engagement and outcomes. The significant trust and respect for traditional healers in rural communities makes the case for further engaging these practitioners in the elimination of stigma, promotion of specific interventions, and delivery of supportive treatment.

- Family members may have additional vested interest in encouraging treatment adherence in their loved ones and may not necessarily be as overtaxed as the community volunteers who sometimes engage in providing support *(59,60)*.

Doing more with less: mHealth and mobile clinics

- mHealth interventions have gained popularity in many developing countries where access to mobile phones has dramatically increased over the past several years. While owning a mobile phone might still be a luxury in some rural communities, community health workers can utilize them to interact with diagnostics and treatment facilities, report on complications and progress in the treatment of some patients, and engage in furthering their training. In one study, when mobile phones were purchased for community health workers, they did not have to spend time travelling from hospital to village and were therefore able to provide adherence reports, make appointments for people with TB, and make field inquiries to physicians via text messages or calls. As a result, the capacity of the rural TB treatment programme was doubled and money was saved *(61)*.

- Médecins Sans Frontières-instituted mobile clinics have been successful in tracking and treating patients for TB and other conditions in the rural communities of South Africa. Mobile clinics allow for regular patient follow-up and are especially convenient for rural residents who rely on seasonal work and so might themselves be mobile.

Mobilizing people with TB: TB clubs

- "TB Clubs" – support groups for TB patients – are said to be effective in battling internalized stigma. Internalized stigma can pose a significant barrier to treatment among people with TB, who might experience treatment fatigue from prolonged courses of medications and a diminished sense of self-worth. Thus, increasing support and expanding patients' support networks could be extremely beneficial for treatment outcomes *(62)*.

Recommendations

While these recommendations provide an outline for action for a range of key stakeholders, others, including UN Agencies and local and global health worker collectives, should take note and assess their potential for use in improving TB prevention, treatment and care for the rural poor.

Civil Society	Groups of Rural People with TB	National Governments and Health Systems	Donors
Advocate at the local level for higher levels of transparency and access to information on rural health service delivery; Create learning opportunities for all community members in navigating health systems and receiving adequate health services; Create opportunities for people with TB to organize and convene in order to expand their support networks and knowledge about TB diagnosis and treatment;	Establish informal networks and organizations of people with TB in rural communities; Devise an advocacy agenda and work towards expanding access to TB diagnosis and treatment; Hold governments accountable and call for transparency on how TB services are delivered to the most vulnerable;	Ensure transparency in rural health facilities; experience in other countries has shown that publicizing the lists of medications that patients can receive for free and listing free health care services diminish corruption and allow patients to advocate on their own behalf; Provide opportunities for local community networks of people with TB to monitor and report on service delivery and highlight problems/solutions;	Hold government grantees accountable and call for transparency on how TB services are delivered to the most vulnerable; Invest in community programming that aims to promote patient self-education and advocacy;
Advocate with national health leaders for access to low-literacy materials to expand TB knowledge and battle TB stigma in rural communities, especially among women, and for the implementation of innovative interventions;	Make decisions as to the best strategies with which to educate peers about TB and the importance of medication adherence;	Produce easy to understand health communication materials on TB symptoms and treatment for low-literacy populations in order to increase knowledge; ensure that these materials are positive and encouraging, and help battle stigma; consult with community advocates on what messages are key to these materials; ensure that the most vulnerable rural populations, such as rural women, are included both as audiences for these messages and in the design of interventions;	Promote and invest in low-literacy materials for rural communities;

Civil Society	Groups of Rural People with TB	National Governments and Health Systems	Donors
Advocate for engagement in the design of interventions that are efficient and cost–effective, and best fit the needs of rural communities;	Be vocal about the needs of rural people with TB; conduct advocacy at the local level and seek ways to speak to national stakeholders;	Explore innovative and cost–effective ways of system-wide health care delivery for TB in rural communities, such as mHealth, community worker interventions, family-supported DOTs, traditional healer engagement, and training;	Promote across settings and invest in the scale-up of cost–effective interventions that can increase access to treatment for rural communities;
Work with rural community leaders to help develop and promote these interventions; Work with community leaders to eliminate stigma through education and support; Ensure that women and children in the community have access to knowledge and education about TB; Advocate for programming specific to indigenous groups; Encourage family member, traditional healer, and community health worker participation in all aspects of TB diagnosis and treatment provision;	Focus on engaging specific population groups that might be additionally marginalized among rural people with TB (e.g., women, migrant workers) and ensure that they are properly engaged in advocacy work and benefit from the expansion of access to treatment; Work with families and traditional healers to encourage cohesive and joint programming to overcome TB in the community;	Promote full community engagement in the delivery of TB prevention, treatment and care; Engage with traditional healers and community health workers to foster educational programmes for both and to create opportunities and incentives for these groups to participate in health care delivery to rural communities; ensure that there is specific programming directed at indigenous groups;	Support holistic programmes that benefit entire communities and engage leaders, traditional healers, and patient and other advocacy groups;
Advocate for better legal frameworks that eliminate barriers for workers and women with TB;	Monitor and report violations in employment and in access to property and land for women with TB/widows of people with TB;	Establish mechanisms for the review of laws, policies and practices that might negatively impact people with TB;	Support the legal and policy review of laws related to the wellbeing of people with TB;
Work with health worker unions and collectives to battle stigma among health workers and to ensure adequate health services in rural areas.	Monitor and report on violations in the health sector and advocate for adequate funding to rural hospitals and health care systems, especially in TB service provision.	Institute incentives for health workers to engage in rural areas; monitor and improve programming incentives for health workers in order to ensure sustainability.	Support and disseminate best practice on incentives for rural health workers.

Resources

Axshya SAMVD: an innovative case finding strategy for tuberculosis care and control. Health. 2014;10 (http://www.researchgate.net/profile/Banuru_Prasad/publication/260434528_Axshya_SAMVAD_An_innovative_Case-Finding_Strategy_for_Tuberculosis_Care_and_Control/links/0f31753147d55b17bb000000.pdf).

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