

# GENDER AND TB

A STOP TB PARTNERSHIP PAPER



Stop **TB** Partnership

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# Abbreviations

<b>CRG</b>	Community, Rights and Gender
<b>EPTB</b>	Extrapulmonary tuberculosis
<b>GAC</b>	Global Affairs Canada
<b>GFATM</b>	Global Fund to Fight AIDS, Tuberculosis and Malaria
<b>HIV</b>	Human immunodeficiency virus
<b>LGBTI</b>	Lesbian, gay, bisexual, transgender and intersex
<b>LTFU</b>	Loss to follow up
<b>M:F</b>	Male:Female
<b>MDR-TB</b>	Multidrug-resistant tuberculosis, defined as resistance to rifampicin and isoniazid
<b>M&amp;E</b>	Monitoring and evaluation
<b>NTP</b>	National TB Program
<b>SDGs</b>	Sustainable Development Goals
<b>TB</b>	Tuberculosis
<b>STP</b>	Stop TB Partnership
<b>UNHLM</b>	UN high level meeting
<b>USAID</b>	United States Agency for International Development
<b>WHO</b>	World Health Organization

This paper provides overview perspectives, which are not generalizable to specific settings. We note that regional specificities will often provide alternative examples to the points we make here. This paper is also a living document. It will be updated as new literature and further results from TB REACH and CRG initiatives emerge. It is intended to be used by all stakeholders in the fight against TB, including the TB community, governments, advocates, academia, donors, innovators and civil society.





# Key definitions

**Barriers and facilitators to care:** “barriers” to health care are any conditions that are inhibiting or stopping access to health care, treatment and support. “Facilitators” to care are conditions that assist or improve health care access and use. Understanding both barriers and facilitators is important because improved TB services require overcoming barriers and strengthening facilitators.

**Community:** a group of people with diverse characteristics who are linked by social ties, share common perspectives, and engage in joint action in geographical locations or settings.

**Community-led monitoring:** a form of public oversight driven by TB affected community as actual beneficiaries of services to increase the accountability and drive TB service delivery improvements. It recognizes that TB affected community are active holders of fundamental rights and not merely passive users of services and provides strong evidence for advocacy with providers and policy makers to improve availability, accessibility, acceptability and quality of services.

**Community, rights and gender (CRG) in TB response:** meaningful engagement of TB affected community, and application of human rights and gender approaches in planning, implementation, monitoring and evaluation of TB programs.

**Community, rights and gender assessment:** A community led and country owned process that, through an inclusive and multi-sectoral approach, generates strategic information for the development of national action plans towards rights-based, gender-transformative and people-centered TB responses.

**Gender:** a socially constructed set of norms, roles, behaviors, activities and attributes that a given society considers appropriate or valued for women, men and transgender people. Gender is often simplistically understood as relating to biological sex and referring only to men and women. However, some people do not fit into, or associate with, these binary categories in terms of biology and identity.

**Gender-sensitive approach:** laws, policies, programs or training modules that recognize that there are different gendered actors (women, men, girls, boys, transgender and gender diverse individuals) within a society, that these individuals are constrained in different and often unequal ways and may therefore have differing and sometimes conflicting perceptions, needs, interests and priorities.

**Gender-transformative approach:** program, laws, policies or training modules that incorporate a tailored approach to respond to the different gendered risks, needs and barriers to services for all people (women, men, girls, boys, transgender and gender diverse individuals).

**Gender-transformative approach to TB:** an approach that examines, questions, and changes harmful gender norms and inequalities for improved rights and health for all people affected by TB

**Human rights-based approach to TB:** upholding the rights of people affected by TB, including the rights to life, health, non-discrimination, privacy, informed consent, housing, food, and water. The approach focuses on the social and economic determinants of the disease, addressing stigma, discrimination, and environmental conditions. It articulates the domestic and international legal obligations of governments and non-state actors to ensure that quality testing and treatment for TB is available and accessible without discrimination.

**Sex:** the classification of people as male, female or intersex based on a combination of bodily characteristics including chromosomes, hormones, internal reproductive organs, and genitalia. This usually happens at birth.

**TB response:** the current efforts to prevent and treat TB as guided by the End TB Strategy and the Stop TB Partnership Global plan to End TB. It includes a mix of biomedical, public health target and socioeconomic interventions along with research and innovation at global and country level.

**Key and vulnerable populations:** people who are vulnerable, undeserved or at-risk of TB infection and illness. Key and vulnerable populations tend to be marginalized and experience specific barriers in accessing health care.

**Stigma:** a dynamic process of devaluation that significantly discredits an individual in the eyes of others. Within cultures or settings, certain characteristics are taken up and defined by others as shameful or unworthy.



# Introduction



**The Stop TB Partnership (STP)** supports countries in achieving universal access to tuberculosis (TB) prevention, care, treatment and support services and promotes country- and community-led responses towards a world without TB. The challenge is immense: every minute three people die from TB. STP focuses on fast-tracking new diagnostic tools, adopting innovative approaches to case-finding, and delivering life-saving medicines to those in need. STP takes a community, rights and gender (CRG) approach to TB, placing emphasis on meaningful engagement of TB affected communities, and the application of human rights and gender approaches in planning, implementation, monitoring and evaluation of TB programs. STP further recognizes that inclusion and protection of vulnerable groups is central to achieving universal access to TB care<sup>1</sup> and that the socio-economic and cultural needs of all people affected by TB should be addressed and dignity should be assured. Concurrently, the promotion and protection of human rights, stigma elimination, gender, other equality, and social inclusion are required throughout the entire TB response.

The STP gender-based approach is aligned with the 2015 Sustainable Development Goals (SDG) agenda, which builds on the recognition that gender equality leads to better development outcomes. Gender equity is both a specific goal (SDG 5) and integrated across all 17 SDG.<sup>2</sup> This approach also aligns with the commitments of the 2018 UN High Level Meeting on TB, in which Heads of States and government representatives not only reaffirmed their commitment to ending the TB epidemic by 2030, but also committed to addressing gender inequality and developing integrated, people-centred, community-based and gender-responsive health services based on human rights.<sup>3</sup> In line with the UN-HLM commitment and community TB priorities, a gender-based approach is strongly reiterated in the Calls to Action from the TB community report *A Deadly Divide: TB Commitments vs. TB Realities*.<sup>4</sup>

The STP approach to gender has been spearheaded through two intervention areas. Firstly, with support from USAID and the Global Fund to Fight AIDS, Tuberculosis and Malaria (GFATM), STP has assisted countries to integrate CRG into their TB responses. By the end of 2020, with support from STP, 20 countries completed CRG assessments<sup>5</sup> through which they have examined the country context in relation to CRG. In addition, 5 countries have continued to complete national costed TB CRG Action Plans; 4 countries have begun the process of conducting TB stigma assessments; 14 and countries have implemented community-led interventions to monitor human rights violations, barriers to TB care and support services, TB stigma and gender related barriers. Beyond this, 31 grants were awarded through Challenge Facility for Civil Society.<sup>6</sup> These grants have supported the integration of CRG into TB responses. They have also supported networks of people affected by TB to advance human rights and gender initiatives resulting in work such as the formation TBWOMEN<sup>7</sup>, a global network of women in their diversity advancing a gender-transformative TB response; a new declaration of rights of people affected by TB<sup>8</sup>; and a guide to implementing a rights-based tuberculosis response.<sup>9</sup> Collectively, these initiatives – amongst other things – provide strategic information on the ways in which gender norms shape TB vulnerability, participation, care access and quality, and treatment outcomes, as well as ways to overcome these challenges. To support and encourage investment in CRG work STP developed 7 TB CRG Investment packages, including the TB and Gender CRG Investment Package.<sup>10</sup>

Secondly, TB REACH is STP's funding platform for innovative projects and approaches to improve TB care delivery and is primarily supported by GAC (Global Affairs Canada). TB REACH has focused on supporting partners to empower women and girls (including transgender women) as part of their TB programmes and interventions. TB REACH Wave 6 grantees (projects initiated in 2018) were requested to provide gender action plans from all applicants and STP conducted a workshop for all grantees on how gender, and the empowerment of women can be incorporated into TB REACH projects. Wave 7 grantees (projects initiated in 2019) were further required to include a focus on empowerment of women and girls as a substantive component of their proposed programmatic activities, their organizational practices, or both. These projects are also required to monitor and evaluate their programs through the generation and use of sex disaggregated data and through clear indicators that assess the impact of their women's empowerment approach. While Wave 7 projects have been hampered by the challenges and lockdowns the Covid-19 pandemic has brought, all are still in operation at the beginning of 2021, and some positive trends in relation to women's empowerment are emerging.

Despite the growing impetus and support for a gender-based TB response at an international level, and despite an established history of a gender-based approach to HIV, integration of gender into TB programming has been hampered by a lack of consensus about what this should mean in practice and a dearth of guidelines for the programmatic implementation of a gender-based response. Furthermore, perspectives differ on the extent to which a women's empowerment approach should be included in the TB response, given that TB epidemiology points towards men experiencing higher rates of disease. In this context, the STP CRG and TB REACH funded work have forged new ground, led to new insights, and have resulted in clarity of perspective, all of which are outlined in this paper.



This paper draws on published literature related to TB and gender, the experience of TB REACH work, and the findings of the CRG assessments to:

- Synthesize what is known about gender and TB burden, care and treatment outcomes
- Highlight current issues of gender inequality in the TB response by setting out ways in which the TB response currently reinforces negative gender norms and current barriers to change
- Suggest ways forward for a TB response that both meets the gender-based needs of all people affected by TB and serves to improve the general position of women and girls in society



A gender-based TB response must find a balance between assessing and addressing epidemiological gender differences and broader economic, social and cultural gender differences. All people – men, boys, women, girls and gender minorities – should be provided with TB care and support services that are available, accessible, acceptable, and of a high quality, free from discrimination and stigma.

The relatively higher burden of TB and greater gaps in care among men, suggest that meeting men's care and treatment needs is a priority. This can, for example, include programs that include healthcare access times that allow for work requirements, or to the relative difficulties men may face in accessing care in contexts, such as South Africa where clinics may be seen as more female friendly.<sup>11</sup> However, gender-based programming must not stop here. Gender inequality and systemic discrimination against women, girls and gender diverse people is an international phenomenon, which manifests in every aspect of life. For example, women only have rights equal to those of men in 6 countries and globally less than 15% of all landowners are women.<sup>12</sup> Women are at greater risk of malnutrition than men<sup>13</sup> and report greater food insecurity in 2/3 of 141 countries.<sup>14</sup> Women are also twice as likely to be illiterate than men.<sup>15</sup> Women have less access to employment, and – even in senior positions – are globally paid 20% less than men for equivalent work.<sup>16</sup> Women also have less control over their health decisions,<sup>17</sup> because social norms often require permission and finances from male counterparts. Inequality and discriminatory practices are also widespread in the way that health systems and services are designed and implemented. In the TB sector this includes, among other things, expectations of free, volunteer labour from community health workers, exclusion of women from technical and leadership roles, insufficient protections for lower-tier workers who tend to be women, lack of provisions (such as toilets) in the workplace for women, lack appropriate diagnostic processes and procedures, pervasive stigma of gender diverse people and exclusion of gender diverse people from data collection and analysis processes. As this paper demonstrates, gender blind TB programming – programming that ignores systemic gender inequities – are common in the TB sector, **resulting in the reinforcement and perpetuation of harmful societal gender norms, which, in turn, undermine health for all.**<sup>18</sup>

Many publications, including *The Impact of COVID-19 on the TB Response: A Community Perspective*,<sup>19</sup> note that the pandemic has further exacerbated existing barriers and challenges, while also creating new human rights and gender related issues which require further understanding and consideration in the context of TB and gender. In this context, gender responsive programming, which actively acknowledges and seeks to change harmful gender norms, is particularly important. It can improve the position of women, girls, and gender minorities in communities and society, which, in turn has a positive impact on health. A women's empowerment approach is therefore both a pragmatic and ethical imperative.

Throughout the paper "gender" does not equate to biological sex, but rather refers to socially constructed roles and relationships, personality traits, attitudes, behaviours, values, relative power and influence that society assumes relate to the sexes.<sup>20</sup> The predominant focus in this paper on gender as it refers to men and women is due to the lack of evidence about people who do not ascribe to gender norms. Gender diverse people face specific challenges that should always be considered in the TB response. Detailed discussions on the various TB key populations<sup>21</sup> is beyond the scope of this paper. Readers are also encouraged to recognize that gender intersects – sometimes in very specific ways – with other marginalising factors, such as migration, substance use, imprisonment, HIV status, and some highly gendered employment sectors such as mining of garment factory work.

This paper provides overview perspectives, which are not generalizable to specific settings. Regional specificities will often provide alternative examples to the points we make here.





# Gender dynamics in TB burden, care and treatment outcomes

## TB epidemiology, sex and gender



Globally, the rates of TB are higher in men than in women (with the notable exception of Afghanistan, where women are consistently shown to experience higher rates of TB.<sup>22</sup> The most recent WHO report estimated that in 2019 women comprised of 32% of all global TB cases (aged  $\geq 15$  years)<sup>23</sup> and men comprised of 56% of cases, with the remaining 12% of being in children (<15 years). Prevalence surveys across 33 countries African and Asian countries between 2007 and 2019, showed that men have consistently higher notifications than women despite the fact that more men than women are missed by the TB response.

The extent of gender differences in TB rates vary by region and country. The 2019 the M:F ratio of incident TB cases for all ages ranged from 1.3 in the WHO Eastern Mediterranean Region to 2.1 in the European and Western Pacific regions.<sup>24</sup> Prevalence studies show M:F ratios ranging from 1.2 (in Ethiopia) to 4.5 (in Viet Nam) for bacteriologically confirmed pulmonary TB. Marked variations in gender differences in TB rates have even been found within countries.

Men and boys also account for a larger share of TB mortality, making up 53% of HIV-negative people who died of TB in 2019, and 57% of HIV-positive TB deaths. That men have a higher TB burden is not, however, universally true or true for all forms of TB. For example, adolescent girls tend to be more susceptible to TB than adolescent boys, possibly due to fluctuating oestrogen levels that compromise immunity and may increase their risk of TB.<sup>25</sup> Furthermore, extrapulmonary TB is more common in women than men and more difficult to diagnose. There is likely therefore some under-reporting of TB in women because prevalence studies tend to exclude adolescents and extra-pulmonary TB (EPTB).

Very little is known about TB epidemiology of gender diverse people and communities, though the data does demonstrate that TB epidemics might be concentrated in communities that are stigmatized and marginalized because of their gender non-conformity. In India, when the national TB program began tracking (2018) TB among persons of the third gender, TB notifications among this group were 426/100,000, compared to 134/100,000 in women and 211/100,000 in men, indicating a high TB burden in this population.<sup>26,27</sup> In Pakistan, a TB REACH intervention implemented by Bridge Consultants Foundation addressed TB in an urban transgender community, and found 1.1% of the 18,272 people screened were found to have TB.<sup>28</sup>

Gender differences in incidence and prevalence ratios between regions and even within countries suggest that cultural and socio-economic factors play a large role in determining TB risk and disease. At the same time, higher rates of TB in men are likely partly a result of biological differences. Sex hormones play an important role in modulating the immune response, with women generally exhibiting a more robust response to antigenic challenges.<sup>29,30</sup> This may partly be due to differences in the metabolism of nutrients, such as iron and fat and differences in the anatomy and physiology of the respiratory tract.<sup>31</sup> Advancements in the fields of immunology, micro- and molecular biology are likely to bring more clarity to the process of TB disease development, particularly TB activation.

Men may also be more affected in terms of morbidity and mortality due to their greater tendency to use substances, inclusive of cigarettes, alcohol and illicit drugs.<sup>32</sup> Smoking has been found to double the risk of TB disease, as well as the risk of recurrent TB disease after successful treatment, and is a significant predictor of the differences in TB burden between men and women.<sup>33</sup> Alcohol use has been found to cause 22 incident cases per 100,000 people.<sup>34</sup> Use of opiates and inhalants and TB risk has been well-established.<sup>35,36,37</sup> Substance use is linked to TB risk both because locations where people gather and use substances can serve as ideal infection transmission environments and also because substance use increases the likelihood of progression from infection to disease.

Incarceration likely also plays a role in the higher number of men with TB.<sup>38</sup> A 2016 review indicates that 2.8% of those imprisoned globally might have active TB<sup>39</sup> and men make up about 93.1% of the approximately 11 million people in prison or detention globally.<sup>39</sup> There is also evidence that TB in prisons has a significant impact on TB epidemiology in countries.<sup>40</sup> Exposure in prisons has been linked to 6.3% of TB in the general population in low- and middle-income settings<sup>41</sup> and mass incarceration in Eastern Europe and Central Asia has been associated with an increase in TB prevalence in the general population.<sup>42</sup>

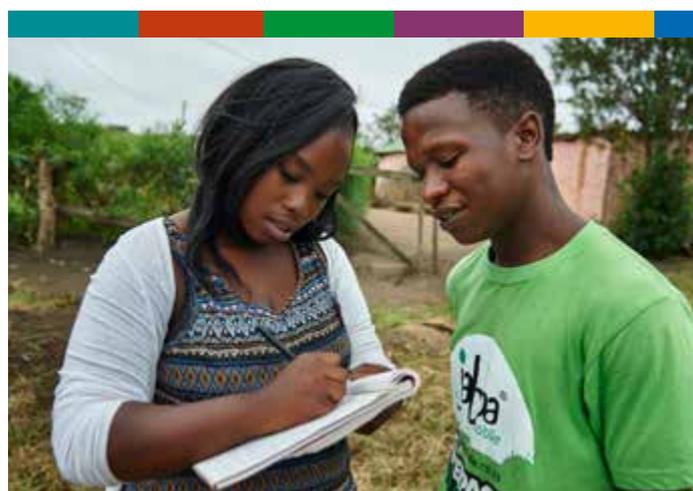




Certain industries that are linked to TB exposure and disease, such as mining and construction are, further, male-dominated, likely also feeding into the higher number of men with TB. Finally, diabetes, which is an important TB risk factor, is generally more prevalent in men than women, which may also contribute to the higher burden experienced by men, though evidence for this is limited. One study found that diabetes results in higher TB morbidity in women.<sup>43</sup>

While the above risks are weighted towards men, there are also risks that are weighted towards women. HIV increases the risk of TB over ten-fold, and is more prevalent in women than men.<sup>44</sup> Yet this does not seem to translate to proportional increases in women with TB, or notably different treatment outcomes to those found elsewhere in countries where this has been explored.<sup>45,46</sup> Malnutrition, which weakens the body's immune defences and is the risk factor with the largest attributable fraction of TB disease<sup>47</sup> is more common in women than men.<sup>48</sup> The CRG assessment in India, a country where over half of all women are anaemic and one in five are underweight, indicated that malnutrition not only substantially increases risk of TB disease in women, it also undermines treatment adherence. Malnutrition in adolescent girls documented in some regions<sup>49</sup> may be one factor that explains the reduced gender gap in TB rates in this age group.

Certain female-dominated professions also have a high risk of TB. This includes the lower echelons of healthcare providers, particularly nursing and community health work. Sufficient measure to protect these workers are often not in place.<sup>50</sup> Women employed in the garment industry may also be at an increased risk of TB which has been documented in a few studies, and noted in TB REACH work.<sup>51,52</sup> Women also face greater risks of being infected at home and due to their care roles, with some evidence that this is partly related to male partners who have not accessed care.<sup>53</sup>



## Gender and care access, care quality and treatment outcomes

Though it is not universal,<sup>54,55</sup> men generally take longer to access TB care than women. Notions of masculinity and the need to exhibit fortitude can inhibit health-seeking and encourage prolonged self-medication.<sup>56</sup> When men do access healthcare, their greater financial freedom means that they are more likely to access services provided outside the public sector. This includes private healthcare providers who may not have the same screening and diagnostic processes as public healthcare providers<sup>57</sup> and traditional healthcare providers, resulting in delayed diagnosis. In sub-Saharan Africa, healthcare facilities tend to be structured towards the needs of women and children, resulting in care spaces that may be difficult to approach (and sit and wait in) for men.<sup>58</sup> Greater levels of formal employment in men, along with their role as breadwinners for their families and households can also inhibit care access;<sup>59</sup> men may not be able to get time off work and may fear loss of employment if they are diagnosed with TB. Men are also more likely to be employed as migrant workers, undermining their ability to remain in care for the full treatment duration.<sup>60</sup>

Men's higher rates of substance use not only increases their TB risk. Substance use also undermines care access<sup>61</sup> and is associated with poor treatment outcomes.<sup>62,63</sup> Furthermore, people who use substance may face substantial stigma in the healthcare sector, and given that substance use, healthcare providers can be reluctant to provide treatment to people who are identified as using substances.<sup>64</sup>

Women are documented to generally have better health-seeking behaviours, but cultural and socio-economic challenges more often delay or block their access to TB care.<sup>65</sup> This includes the high burden of housework, lack of health literacy, lack of access to finances or resources and decision-making powers lying with male family members. Not only are women less likely to have financial autonomy, when they do have their own earnings these are often lower than that of men, so costs of TB care account for a greater proportion of their income.<sup>66</sup> Limited mobility for women in many settings also hampers their ability to seek healthcare.<sup>67</sup> Women are also often reliant on permission and support from their partners to access care, or undertake any treatment process. The ways that societal gender discrimination hampers equal access to healthcare is particularly evident in the CRG assessment reports from Eastern Europe and Central Asia and South East Asia.<sup>68</sup> This was also evident in TB REACH grantee work in Tanzania.



There are also numerous documented reasons that women may have greater difficulties getting a diagnosis. Healthcare providers are less likely to suspect TB in women as the “typical” person with TB is seen to be male.<sup>69</sup> Related to this, women are less likely to be sent for sputum samples and when they are sent tend to have greater difficulty producing quality sputum samples,<sup>70</sup> perhaps resulting in under-detection.<sup>71</sup> Introduction of sputum production instructions for women in Pakistan significantly increased the rate of smear positive TB among women.<sup>72</sup>

TB symptoms may, further, not be noted in pregnant women, or by healthcare providers because the symptoms may be assumed to be the result of pregnancy. One study found symptom screening to have a sensitivity of only 28%.<sup>73</sup> Diagnosis in pregnant women is further undermined by the difficulties of using chest X-rays in pregnant women. Similarly, genital TB can be difficult to diagnose because it may be asymptomatic, or the symptoms, such as irregular menstrual cycles, may not be interpreted as potentially indicative of TB. High TB prevalence countries also often lack culture and histopathology services that are needed for diagnosis of genital TB.<sup>74</sup>

Challenges in accessing health care are best documented for gender diverse people in developed countries and highlight the pervasive discrimination, stigma, breaches of confidentiality and other issues that discourage gender diverse people from accessing services.<sup>75</sup> Criminalization of same sex behaviour and morality laws limiting freedom of expression of gender diverse and lesbian, gay, bisexual, transgender and intersex (LGBTI) people further lead to violence against gender diverse and LGBTI people and widespread stigma and discrimination, including in healthcare settings, reduces service access.

Loss to follow up (LTFU) has been documented to be similar in men and women in some contexts<sup>76,77</sup> while elsewhere it has been found to be twice as high in men as women with multidrug-resistant tuberculosis (MDR-TB).<sup>78</sup> The gender factors that impact health seeking behaviour also impact retention in care. For example, women’s need to get permission from male figure-heads for care processes<sup>79</sup> and men’s greater involvement in migratory occupations can impact their respective ability to stay in care. TB REACH experiences in India have also indicated that LTFU in men may not necessarily suggest a lack of treatment completion, but rather that having greater financial resources may enable them to continue care in the private sector after the initial diagnosis and initiation on treatment, resulting in a disruption on reporting processes.<sup>80</sup>

Gender inequality not only shapes access to care, it also shapes the impact of infection. For example, men are more likely to be in formal employment and face termination when they are diagnosed with TB. The burden of care for relatives and community members is overwhelmingly carried by women,<sup>81</sup> who also face increased home care responsibilities when male partners become very ill or die. TB related stigma remains pervasive and – while experiences across the board – is also shaped by gender. In South East Asia, stigma associated with TB can mark women as unmarriageable,<sup>82</sup> and married women with TB may be forced to leave their home if diagnosed with TB.







# Gender inequality and the TB response



It is clear from the preceding sections, that gender matters because it shapes TB risk and influences care accessibility, availability, acceptability, and quality, which in turn impacts on the impact of infection and health outcomes. A gender-based approach, which responds to biological and social, cultural and economic differences is, therefore, critical, to find those who are currently missed by the response and to provide effective, inclusive TB services that meet the needs of all people. The higher TB burden in men means men warrant specific programming. At the same time, gender equity is a basic human right which, presented in this section, is not being met in the TB response. Rather, the TB response often reinforces, or risks reinforcing societal gender discrimination in several ways, including:

- **Power, protection and remuneration in the health workforce including the TB workforce.** Senior, decision-making positions in the health-care sector and TB response, including in government, private, community and entrepreneur sectors, are largely filled by men while the vast majority of primary healthcare workers, inclusive of care workers, facility-based staff and laboratory technicians are women. Lower tier health-care positions are female dominated. These positions have less access to personal protective equipment and less access to compensation for occupational infection, which in turn can inhibit their financial ability to access care required in cases of occupationally acquired TB disease.
- **Reliance on poorly paid, or unpaid female community health workers.** The notion that women's work is not valuable is reinforced by expectations of free or poorly paid work by women. This can add to the food insecurity, psychological distress, and reduced social security experienced by women, as was illustrated by work done by Women Development Army in Ethiopia.<sup>83</sup>

- **Exclusion and stigmatisation of gender diverse people.** Gender diverse people are frequently excluded in data collection, analysis and use processes<sup>84</sup> (including prevalence studies and monitoring and evaluation processes) and from meaningful participation in program design and management. This exclusion results in a lack of attention to the needs of gender diverse people. Furthermore, stigma towards gender diverse people is pervasive in the health system generally<sup>85</sup> and has been found in CRG Assessments in South Africa and India.
  - **Counselling processes and IEC materials that reinforce patriarchal gender roles.** The notion that women are “natural” caretakers permeates the messaging provided by many TB program. Women are counselled to take responsibility for caring for children and sick relatives, ensuring male partners take medication and contact tracing in a way that is not habitually expected of men. Information and education materials frequently represent women as lower tier care-takers, and care providers in the home, and men as senior healthcare providers. Together these reinforce gender inequalities and add to women’s care burden.
  - **Lack of information and care provision for women in TB key and vulnerable populations.** Information on TB in women in male dominated key and vulnerable populations (such as the mining sector, prisons, people who use drugs) is lacking, as is service provision for women in these groups. This results in people with TB being missed. A recently initiated TB REACH project in a women’s prison in Peru diagnosed nine women with TB in the first month of operation, in a prison that has previously averaged five diagnoses per year.<sup>86</sup> There is a lack of available information on TB service provision for women who use drugs, suggesting that they are and habitually left out of TB interventions.
  - **Lack of appropriate diagnostic processes and procedures.** Given that diagnosis of TB is often more difficult in women, diagnostic algorithms need to be designed to meet women’s needs. This should include sufficiently sensitive screening and diagnosis for pregnant women, women with genital TB, and women who cannot provide sputum, yet these are frequently not part of routine case finding processes.
  - **Lack of investment and coordination in terms of TB and gender related barriers, monitoring, advocacy and accountability.** In a context of societal inequality, ensuring that women’s voices and needs are recognized and brought to the fore requires active, co-ordinated efforts that are driven and assessed by women, and listened to and supported by the broader TB community. The newly formed TBWomen can help us to close this gap.
- Change towards a gender-based TB response that provides for the gendered TB risks and needs and also works towards a gender-equitable society more broadly is a practical and ethical imperative. The misunderstanding that a gender-based TB response either meets the needs of men due to their greater TB burden, or emphasizes women’s vulnerability and health needs, serves as an important barrier to change. This paper suggests that these approaches are not contradictory, but rather can be complementary. Further notable barriers to change towards a more gender-responsive TB programming include:
- **Lack of contextual information and knowledge.** Some gender-related TB dynamics are broadly similar the world over, whereas others are very contextually specific. This means that the recognition that gender matters for the TB response needs to be accompanied by corresponding research and analysis at a local level to provide strategic information for change.
  - **Overemphasis on epidemiology and biomedical responses without recognition of social dynamics.** The social drivers of TB play a critical role in fuelling the TB epidemic. Inadequate attention to this undermines the TB response and misdirects attention away from gender.
  - **Lack of sensitization.** While there is growing research and documentation of the impact of gender on TB infection, disease, care and outcomes, STP work has demonstrated the extent to which the knowledge does not always extend through National TB Programmes (NTPs) and health care providers. Consequently, gender blind practices and approaches remain common.
  - **Lack of capacity and skills to implement a gender-responsive approach.** Despite recognition of the need to take gender into account in the TB response, individuals and organisations do not always have the skills, knowledge or capacity to turn this knowledge into action.





# Solutions and best practices

STP recommends three areas for focus for a gender-based TB response, which are further elaborated below. These are:

1. **Generating, understanding and using evidence**
2. **Ensuring a comprehensive, sustainable gender-responsive approach in all aspects of planning and programming**
3. **Promoting gender equality through programming that empowers women and girls**



## Generating, understanding and using data

The collection, interpretation and use of qualitative and quantitative data about gender and TB is key to designing and implementing appropriate gender-responsive interventions and assessing their impact. There are three essential elements to successful data generation and use:

- **Undertake a TB gender assessment and develop a national costed TB CRG Action Plan.** As part of a TB CRG Assessment, undertake a gender analysis, or assessment, that includes a literature review, analysis and interpretation of gender disaggregated quantitative data throughout the TB care cascade, and collection of qualitative data. Analyses should include women, men and gender diverse people and incorporate a focus on particularly vulnerable and marginalized populations. The focus should be on strategic information that can address knowledge gaps and change requirements required for quality and equitable treatment access and provision – as well as equitable access to social protection mechanisms. The information generated should be used to inform and budget gender-responsive policy development, advocacy, TB programming and assessment indicators and standards that can be monitored and are integrated into the NSP.



## Ensuring a comprehensive, sustainable gender-responsive approach to TB

A comprehensive gender-responsive TB approach has a number of elements above and beyond data informed gender-responsive program design, implementation and assessment. All stakeholders should be sensitized to the importance of a gender-based approach to TB; capacity building to enable the design, implementation and assessment of a gender-based approach should be undertaken with stakeholders and implementing parties; and TB institutions should themselves be representative of a gender-responsive structure and approach.

- **Gender sensitisation and training.** A solid understanding of how gender affects TB and how TB affects gender and, correspondingly, the importance of a gender-responsive TB approach in all TB stakeholders is essential for support for a gender-responsive approach. TB REACH projects have demonstrated the positive impact of gender sensitivity training in TB program implementers.
- **Gender-based capacity building.** In order to support the translation of knowledge to action and ensure sustainability, TB stakeholders, including TB-affected communities, NTPs, program managers and implementers at all levels should be capacitated to take a gender-based approach. The specific focus of this capacity building will vary by stakeholder role, but should, for example, include training on how to provide gender sensitive care (including case finding, diagnosis, and counselling processes), how to analyse and effectively respond to gender disaggregated data, and how to manage gender dynamics in the workplace. A CFCS project in Ukraine is supporting the development of a gender-sensitive TB care counselling algorithm for people with TB.

- **Ensure routine collection, analysis and use of sex and age disaggregated data.** Comprehensive collection and use of sex and gender disaggregated data at all stages of the TB care cascade provides insight into the differences between men and women, boys, girls and gender diverse people in terms of their TB risk, diagnosis, treatment initiation and treatment completion. It is, therefore, a key resource for the design and evaluation of gender-responsive programming. Data collection and analysis should include sufficient demographic detail, and interpretation of data should be supported by the findings of a gender analysis. Interpretation and use of the data should be consistent and supported by sensitized and knowledgeable TB program staff.
- **Integrate gender into all monitoring and evaluation (M&E) processes.** Integrating gender into M&E of different TB interventions, including community-led monitoring is important to reveal and explain gender gaps in TB outcomes, and address these so as to ensure equity.<sup>87</sup> In addition to the collecting gender disaggregated quantitative data related to TB epidemiology, quantitative and qualitative indicators relating to gender should be incorporated into all M&E processes. Interventions should aim for gender mainstreaming (that recognizes that all interventions, whether focused on gender or not, happen in a context of existing gender relations and aims for gender equality)<sup>88</sup> and assess their broader effects on gender equity and the community in which they are implemented. This should also include routine monitoring of gender related barriers to TB prevention, diagnosis, treatment, care and support (including support from social protection systems) services, human rights violations and TB stigma. This means that all interventions should include M&E indicators that track who and how people participate in the intervention; who benefits from the intervention; how the intervention impacts on gender inequality in the broader community; budgets dedicated to gender related activities; and whether the intervention has impacted on tensions or gender-based violence in the community. It is useful to assess impact at the level of organizational structure and operation, as well as the impact of interventions at a programmatic, individual and societal level.

- **Partnerships with gender organisations.** Organisations focused on gender equity work should support TB programs to take the needs of men, women and gender diverse people into account. At the same time TB programs can and should support gender organisations, such as women's rights organisations, to gain essential TB knowledge so that they can support the TB response through their work. Wave 7 TB REACH projects, PATH in Myanmar and Innovators in Health in India have demonstrated the effectiveness of this approach. DREAMS (Determined, Resilient, Empowered, AIDS-free, Mentored, and Safe women) provides an example from the HIV realm.<sup>89</sup> Given the challenges related to improving men's health seeking behaviour, it is important to also work with organisations that focus on engaging boys and men in promoting gender equality and health equity such as the global MenEngage Alliance.<sup>90</sup>
- **Gender equity in the TB workforce.** A lack of representation in the TB workforce disadvantages everyone; women's needs are less taken into account when women are not adequately represented at levels where decisions are taken. Men, on the other hand, may benefit from having other men provide primary care that is currently provided by women. Key steps in creating a gender equitable workforce include the development of gender equity policies, ensuring gender representation at all levels, training and capacity building of women to take on greater leadership roles, developing gender task forces, ensuring adequate and equal protections of all levels of employment.<sup>91</sup>

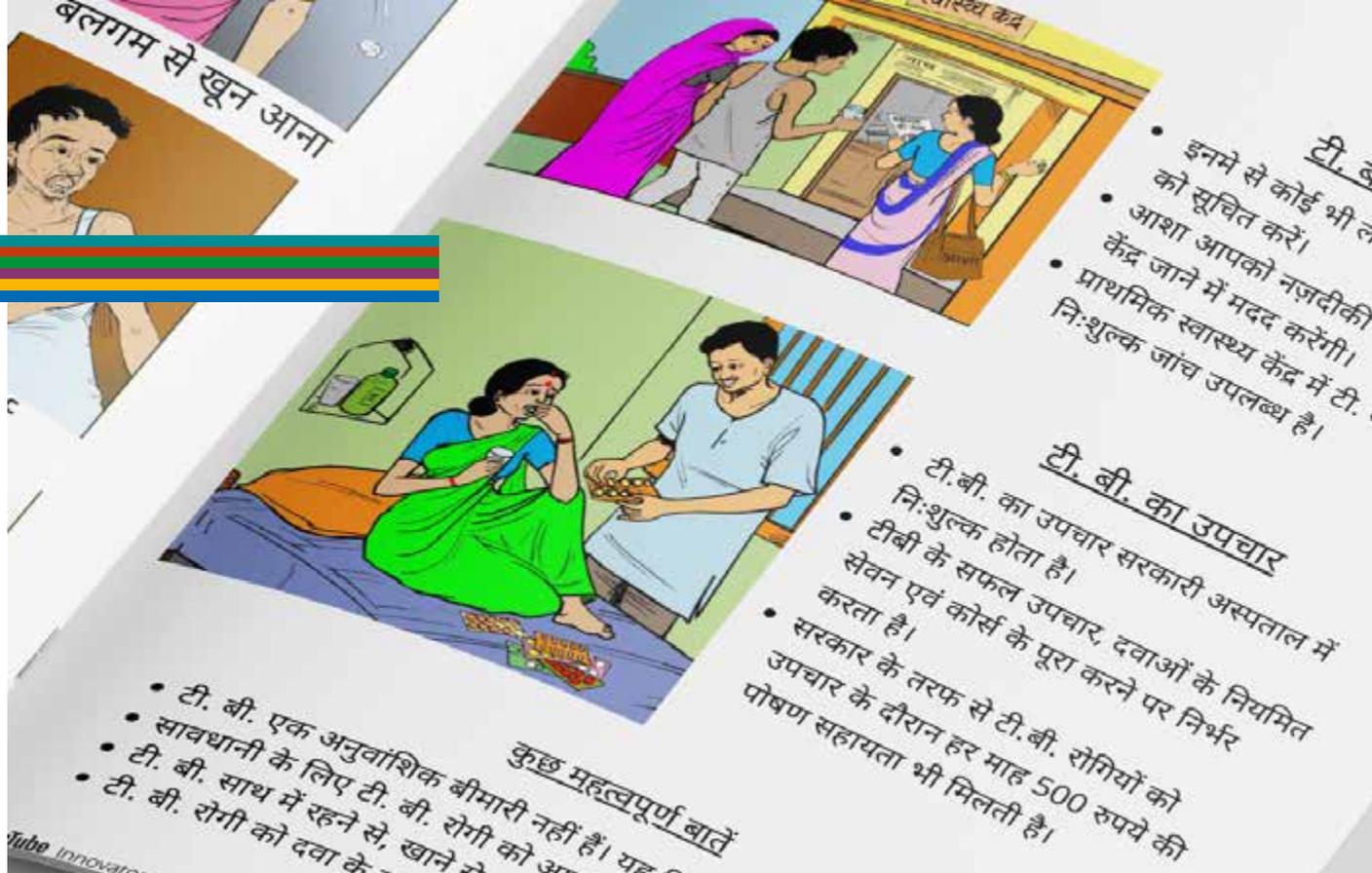


## Promoting gender equality through TB leadership and programs that empower women and girls

"I was quietly in the corner doing household chores. Now when I am able to help someone get better, the way they look at me, the way they treat me is something I can't describe in words...I will cry tears of joy."

Fieldworker, REACH India

The TB response has great power to influence gender equality through advocating for women's rights and working against the systematic discrimination faced by women and girls. TB REACH Wave 7 funded projects were encouraged to take a women's empowerment approach to their work. In addition to the importance of an equitable workforce, these projects, currently being implemented in 2020-2021, are having a notable impact. For example, Innovators in Health (Bihar, India) have reported how capacity building with community health workers, on areas such as digital and financial literacy, and mobility improvement through bicycle training has not only improved women's confidence and decision-making, but also their ability to effectively implement case finding and reporting. Provisional results from Bridge Consultants Foundation in Pakistan show the impact on TB case finding in general through empowering female healthcare providers, traditionally excluded from TB care provision, with TB training. This, and others TB REACH projects are also finding that a women's empowerment approach is leading to additional attention to paediatric TB.<sup>92</sup> Overall, the TB REACH Wave 7 projects highlight some important and viable options for women's empowerment through the TB response:



- **Upskilling of TB care provision knowledge in female health care providers.** Female health-care providers currently not working in the TB sector can be brought into the TB sector through targeted recruitment and training. This has been proven to facilitate involvement and leadership of women in the TB response, improve the TB response by enlarging the pool of TB care providers, and increase the number of people with TB diagnosed and started on treatment in the areas where the interventions are being conducted.
- **Development of other skills in women and girls in the TB response.** Women and girls engaged in the TB response may be limited in their capacity to make their own decisions and act on them by socio-cultural norms about education and behaviour. Wave 7 projects have successfully integrated skills building in areas as diverse as leadership, digital literacy, community-led monitoring, advocacy, financial literacy, bicycle riding training for mobility, and research. Early results indicate that this is resulting in improved work skills and increased confidence levels.
- **Inclusion of boys and men.** The burden of gender equity in TB programming should not rest on the shoulders of women and girls. TB program can and should work with men to ensure that they support gender equity and are engaged in movements towards this. This can include engaging male community leaders to educate and inform other men about TB and women's rights.<sup>93</sup>

"I took this challenge because of the previous 'prohibition' on [women getting services]... Now I am bold enough to counsel males as well"  
Female doctor, recently trained in TB care provision, Bridge, Pakistan

- **Generation of gender-responsive TB materials and resources.** All TB materials can be designed to work against gender-based myths related to TB, and demonstrate gender equity. For example, information and education materials should represent men as care providers, and women as senior healthcare providers.

In addition, in 2020 Stop TB supported the development of TBWOMEN a global network. This has the vision to ensure a just and inclusive society, where women in all our diversity are empowered to realize a world free from TB and the mission to build a coordinated movement for a gender transformative TB response through women's mobilization, empowerment, policy advocacy, innovation, evidence building and knowledge sharing. Stop TB Partnership will look to further the advancement of TB and gender, and promoted gender equality, in close partnership with this global network.



**In conclusion:**

# Positive change from gender-responsive programming

The discourse on gender has, until recently, largely focused on setting out the ways in which gender shapes TB risks, care provision and treatment outcomes, with a focus on TB epidemiology. This is imperative for effective and rights-based care provision, but it is only the first step. Health programming, including TB programming can and should incorporate more holistic social and developmental approaches that move beyond biomedical responses and seek to improve the overall wellbeing of the population. Beyond this, the ways in which TB care provision impacts on gender dynamics and TB programming must be recognized.

The Stop TB Partnership CRG assessments, action plans and monitoring overwhelmingly indicate that, once one looks past the numbers, women's position in TB is reflective of their subjugate position in society more broadly. Furthermore, the positive impact of the women's empowerment work done by Wave 7 TB grantees, is starting to be evident and provides a platform of knowledge and experience for future work. TB programming, when well implemented, and when it includes components of capacity building and increased resource access for women and girls can positively impact on gender relations and, therefore, holds an opportunity for a more gender equitable world that is currently very largely unrealized. STP calls diverse TB stakeholders to recognize the potential power of their work and join us in efforts to broaden the discourse and action on gender and TB.



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