THE LIGHT CONSORTIUM

BRIDGING THE GAP FOR ADOLESCENTS AND YOUNG ADULTS WITH TB:

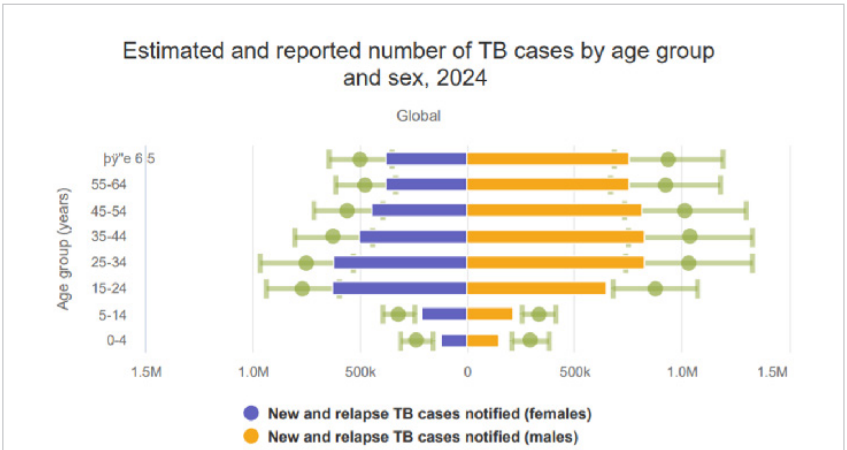
INSIGHTS FROM LIGHT RESEARCH PROGRAMME

MARCH 2026

THE CHALLENGE

Tuberculosis (TB) remains one of the world's top infectious killers. In 2024, an estimated 10.7 million people fell ill with TB and 1.23 million deaths[1]. TB burden is relatively high among young people (15-24 years), contributing nearly one in seven TB cases worldwide, yet their needs remain overlooked in TB research, policy, and programming.

Malawi Photovoice



Source: World Health Organization. TB profile. Available from: WHO 2025 global TB report

Adolescents and young adults (AYA) experience TB through a distinct life stage shaped by schooling, first employment, mobility, and evolving social identities[2]. Increasingly, global health discourse recognises that gender and age intersect to shape exposure, access to care, and treatment outcomes[3].

In line with trends across all age groups, young men are more likely to develop and transmit TB and less likely to test early, initiate treatment promptly, or complete care[4]. Young women may face stigma, family pressures, and confidentiality risks that influence whether they seek care and adhere to treatment, especially when healthcare decisions are shaped by household dynamics[5]. Amid global ambitions to "End TB by 2035", evidence that clearly explains how youth realities and gender norms influence engagement across the TB care continuum - from prevention, diagnosis, treatment, to recovery - remains limited.

Malawi Photovoice

LEAVING NO-ONE BEHIND: TRANSFORMING GENDERED PATHWAYS TO HEALTH FOR TB

Partners:

AFIDEP African Institute for Development Policy

Malawi Liverpool Wellcome Research Programme

mli

ReSOK Respiratory Society of Kenya

Zankli Research Center

London School of Hygiene & Tropical Medicine

LSTM Liverpool School of Tropical Medicine

Funder:

UKaid from the British people

WHAT LIGHT DID

LIGHT used mixed-methods research approaches - including quantitative and qualitative research - in Malawi and Kenya to generate actionable, gender-responsive evidence, working closely with national TB programmes, county and district health authorities, civil society partners, healthcare workers, and young people affected by TB.

MALAWI: UNDERSTANDING GENDERED TB EXPOSURE RISKS AND EXPERIENCES

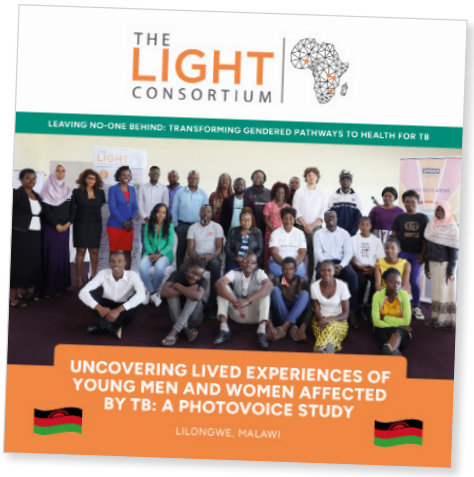
Men have higher TB burden, are often under-diagnosed, delay seeking care, and contribute disproportionately to TB transmission. Therefore, tailored interventions that work for men can reduce TB burden for everyone. LIGHT research partner in Malawi, Malawi Liverpool Wellcome Research Programme (MLW), focused on understanding how sex and age shape TB infection risk and the uptake of community-based TB testing and treatment.

a. Mtb infection study (Blantyre): LIGHT research in Malawi estimated sex-and-age-disaggregated prevalence of Mtb infection among young people and adults in Blantyre. Approximately 3,000 people were tested in Blantyre, showing Mtb infection rates of 8-18%, and a sharp rise in late adolescence. Young men (aged 20-25 years) were 1.2 times more likely to be exposed than women. The generated evidence helped highlight opportunities for reducing Mtb exposure to reduce TB disease risk.

b. Building on these findings, a qualitative follow-up study used a participatory approach and focus group discussions (FGDs) with adult and adolescent males and females, including individuals with positive and negative Mtb exposure test results. The study captured diverse perspectives relating to their knowledge, concerns, and preferences around Mtb infection prevention intervention, focusing on gender and age-specific barriers to uptake of TB preventive treatment (TPT) and forthcoming TB vaccines. This participatory approach, rooted in community dialogue and visual facilitation (spider diagrams and spectrum lines), aligned with LIGHT's commitment to co-producing evidence that informs policy and programme design.

c. LIGHT also conducted a participatory photovoice study with young people with TB and young carers to document their own lived experiences through photos and captions produced by participants themselves. The photos were then used to initiate dialogue with health workers and policymakers about barriers to TB care and what youth-friendly solutions should look like in practice.

Malawi Photovoice Action Workshop



KENYA: STRENGTHENING TB CARE CASCADE FOR ADOLESCENTS AND YOUNG ADULTS IN NAIROBI

In Nairobi, LIGHT partner, Respiratory Society of Kenya (ReSoK), collaborated with the National TB Programme, county health authorities, civil society partners, and young people affected by TB to identify where young people drop out of the TB care cascade and why - using mixed methods approaches including:

a. Quantitative TB care cascade analysis: LIGHT analysed national TB data from all 47 counties and six Nairobi facilities (TB care cascade analysis) to identify where disengagement occurs.

b. Transect walks were conducted to better understand the context of where young people spend time, work, and gather in their communities, and how these environments shape TB exposure and access to services.

c. This was then complemented by qualitative research across six health care facilities that serve the highest number of young people with TB in Nairobi County to better understand barriers and enablers to TB diagnosis, treatment initiation, and treatment completion among adolescents and young adults. The ReSoK team in Kenya conducted in-depth interviews with young people, aged 15-24, diagnosed with TB who initiated treatment but did not complete the full course and disengaged from TB treatment and participatory workshops with young people who initiated and successfully completed treatment completed treatment. The study explored their lived experiences of seeking care across different health facilities and stages of the TB care cascade.

Kenya Youth Workshops

LIGHT FINDINGS

Our findings from Malawi and Kenya research studies suggested that:

1. TB RISK, EXPOSURE, AND WHO IS MOST AFFECTED

- TB infection risk diverges from late adolescence with young men facing higher risk of TB exposure than young women, largely due to high-risk work and leisure environments where TB transmission is more likely.
- Risk behaviours drive exposure: Boys and young men reported much higher tobacco and alcohol use, sometimes up to 8 times, which is strongly linked to increased TB exposure. Photovoice in Malawi also shows that supportive counselling can help some young people reduce harmful alcohol use and improve adherence to treatment, pointing to the importance of integrating psychosocial support into TB services.

2. ENGAGEMENT IN TESTING AND DIAGNOSIS

- Bringing TB services closer to communities increases engagements in TB testing and diagnosis: Community outreach and mobile testing draw more men than hospital-only testing, even when turnout of men and women is similar, 2 out of every 3 people diagnosed with TB were men.
- Young people commonly reported first seeking care at pharmacies and chemists due to easy access, lower costs, and extended operating hours. While this improved initial access, it often delayed entry into formal TB services.
- Once young people are in formal care, many experienced multiple missed or delayed diagnoses, with initial misdiagnoses (e.g. asthma, pneumonia, tonsillitis, and other conditions) leading to prolonged illness, worsening health, significant weight loss, repeated visits, financial strain and frustration. Photovoice study reinforced the heavy cost and repeated care-seeking burden.

3. TREATMENT COMPLETION AND OUTCOMES

- Adolescents aged 15 to 19 years had better treatment outcomes than those aged 20 to 24 years; and females had better treatment outcomes than males.
- TB and treatment side effects can significantly reduce young people's ability to perform daily tasks. Photovoice highlighted that physical limitations disrupt gendered roles- where young women reported disruptions to domestic responsibilities (e.g. fetching water, cooking), and young men reported loss of capacity for labour-intensive work and threats to their "strength" identity – all of which undermine adherence and recovery.

4. BARRIERS TO TB PREVENTION AND CARE AT MULTIPLE LEVELS

- Individual-level barriers: Low awareness around TB in general including TB preventive treatment (TBT), confusion between latent TB and active TB, and the perception that "medication is for sick people" discourages preventive treatment when asymptomatic. Moreover, fear of blood draws, concerns about medication side effects, pill burden, and misinformation (including narratives about witchcraft in some communities) further limit uptake. Requirements for family or guardian consent, particularly for adolescents and young women, can delay treatment initiation or contribute to disengagement with TB care.
- Socio-cultural norms and gendered power dynamics: TB-related stigma is a consistent barrier across all settings. TB symptoms such as chronic cough and weight loss were frequently associated with HIV, fuelling fear of gossip, shame, and social isolation. TPT was also sometimes interpreted as proof of illness, increasing reluctance to start prevention. Gendered household roles and decision-making influence TB prevention and care. For instance, some young women reported taking TPT alone despite shared exposure and preferred long-acting injectable TPT over pills, reflecting both pill burden concerns and the desire for discreet, easier adherence options. Young women also reported carrying a huge burden of caregiving responsibilities which may hinder their access to care. Young men on the other hand, prioritised work over prevention and delayed care due to work demands and perceptions of physical strength. In some households, male heads control health decisions; women who try to pursue TB prevention independently may face conflict. In some cases, TB diagnosis or treatment led to marital conflict or separation.

- Health system barriers included clinic operating hours that conflict with school or work schedules, weekend closures, service interruptions during health worker strikes, long waiting times, unclear communication about test results, and insufficient explanation or support from health care workers on sputum production, limited prevention options offered (e.g., mainly weekly regimens), weak counselling, fear of being recognised in the clinic, unequal access to prevention information, inadequate privacy in drug packaging exacerbating stigma, and perceived discrimination against young people in health facilities.

5. PSYCHOSOCIAL IMPACTS AND LIVED EXPERIENCE

- In addition to the physical impacts reported by young people living with TB – including physical weakness hindering their ability to work or go to school – they reported profound psychosocial harm and emotional distress, including suicidal thoughts linked to stigma and isolation, fear and anxiety (e.g., moral accusations against young women), discrimination, and loss of social life, friends and hobbies.
- Upon receiving a TB diagnosis, young men in Kenya and Malawi reported shock, disbelief, denial, as well as initial non-adherence and even experiences of violence. Nevertheless, a few participants reported relief when TB was finally diagnosed after a prolonged diagnostic journey.

6. ECONOMIC BURDEN AND DISRUPTION TO EDUCATION

- TB imposes major economic pressure through diagnostic journeys, transport costs, loss of income, and risk of debt.
- TB can derail schooling for both young people with TB and caregivers, threatening longer-term prospects, household stability, and future livelihoods, an especially critical concern during adolescence and early adulthood.

7. DROP-OFF POINTS ALONG THE PATHWAY

- Young people disengaged from the TB care cascade at multiple points where many were never screened, never tested even when symptomatic, or struggled to stay on treatment.
- Young men were especially at risk of disengagement, linked to unstable living conditions, loss of treatment support, homelessness, and incarceration (e.g., during the Nairobi Gen Z demonstrations), revealing how social shocks can interrupt treatment continuity.

8. ENABLERS FOR TB TREATMENT INITIATION, COMPLETION AND RECOVERY

- Supportive relationships are central to successful care. Young people reported how health care workers, family members, friends, and community health workers played a critical role in treatment initiation, completion and recovery. This included counselling, reminder phone calls, flexible drug collection arrangements, transport assistance, and home visits.
- Photovoice further highlights coping mechanisms and resilience, including turning to religion or spirituality for hope and emotional strength, alongside practical and emotional support from peers and family.

LIGHT IMPACT

LIGHT's research strengthened the visibility of adolescents and young adults within TB policy and programming, informed youth- and gender-responsive service delivery, and supported improvements in TB data systems, including age- and sex-disaggregated reporting. Findings were used to inform facility-level action planning, national policy dialogue, and ongoing updates to TB strategies, contributing to more equitable and people-centred TB care.

INSTRUMENTAL IMPACT AND ENDURING CONNECTIVITY

1. INFLUENCING POLICY AND PRACTICE

- In Kenya, findings were shared with the National TB Programme, Ministry of Health, and county health departments, informing the development of youth-friendly and gender-responsive TB strategies.
- LIGHT partners in Kenya, ReSoK and AFIDEP (the African Institute for Development Policy), are now recognised as trusted contributors to the national TB response and were invited to support the development of Kenya's school TB policy. Evidence from LIGHT's Kenya studies is informing the policy document: "Policy on Tuberculosis Response in Learning Institutions, Kenya (2025–2035)".
- In Malawi, the National TB & Leprosy Elimination Programme has used LIGHT's research findings to inform Malawi's TB care and prevention services and is now informing the implementation of new TB preventive therapy guidelines and contributing to national discussions on scaling up latent TB testing and treatment.

CONCEPTUAL IMPACT

2. SHAPING GLOBAL TB AND GENDER DISCOURSE

- LIGHT's gendered analysis contributes to the growing global recognition of TB as a gendered disease, aligning with the WHO and Stop TB Partnership's calls for integrated gender-transformative TB programming.
- LIGHT's work reinforces that youth are not merely passive service users but are agents of change, aligning with the Global Plan to End TB (2023–2030) emphasis on equity, participation, and addressing social determinants of health.

CAPACITY STRENGTHENING, CONCEPTUAL AND LONG-TERM IMPACT

3. EMPOWERING YOUTH AND AFFECTED COMMUNITIES

- In both settings, participatory action research methods (including photovoice and co-design approaches) enabled young people to voice their lived experiences and co-design solutions.
- Youth researchers and peer educators involved in dissemination are strengthening local research capacity and driving community advocacy.
- Community outreach testing demonstrated that decentralised approaches could find those most affected, particularly men and young people, link them to care early, thereby, reducing TB transmission in the community, and protecting other men, women and children.

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RECOMMENDATIONS

LIGHT's research underscores that ending TB requires addressing how gender and age intersect across the care continuum, from infection prevention to treatment completion. Key recommendations include:

- Youth-friendly, stigma-free TB services with flexible hours, strong confidentiality safeguards (including discreet packaging and private service delivery points), and improved counselling and communication, including clearer guidance on testing processes, results, sputum production, side effects, and prevention options.
- Decentralised, integrated service delivery across schools, workplaces, and community settings, including mobile/outreach models that effectively reach young men.
- Strengthened routine data systems with consistent age- and sex-disaggregation to identify inequities and track losses for AYA along the TB care cascade.
- Engagement of youth groups in policy design, ensuring interventions reflect lived realities.
- Gender-responsive prevention and adherence support, including approaches that provide mental health and psychosocial support for young people and caregivers, and offer more acceptable prevention options.

Malawi Photovoice

CONCLUSION

LIGHT's research in Malawi and Kenya shows that designing TB care around the real daily lives of young people (privacy, time, money, and dignity) increases engagement from diagnosis through treatment completion. By documenting how gender and youth realities shape TB exposure, care-seeking, and outcomes, LIGHT is helping reframes TB as not only a biomedical issue but also a social justice and equity challenge. Through rigorous mixed-methods research, participatory approaches, meaningful engagement, and policy influence, LIGHT supported a shift toward more youth-friendly and gender-responsive TB prevention and care, positioning young people not just as beneficiaries, but as co-creators of transformation.

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