THE LIGHT CONSORTIUM

FROM LIVED EXPERIENCE TO ACTION:

COMMUNITY-LED TB SOLUTIONS FOR TUBERCULOSIS

MARCH 2026

THE CHALLENGE

Tuberculosis (TB) disproportionately affects marginalised communities, especially men who face systematic barriers to timely diagnosis and care[1]. In the absence of accessible health information, many deprioritise respiratory symptoms or seek temporary, low-cost relief from informal providers[2]. This delay, compounded by TB-related stigma and catastrophic out-of-pocket costs, deepens social marginalisation and fuels community transmission. Consequently, men with untreated TB remain the primary drivers of the epidemic, accounting for 67% of new infections in other men, 52% in women, and 63% in children[3].

Engagement of TB-affected communities is recommended (as shown below) for their lived experience and context expertise, but implementation remains limited[1]. TB survivor stories are powerful tools for advocacy, community awareness, stigma reduction, and quality improvement of TB care and research. However, existing paternalistic programme and service models overlook key assets and resources within communities and thus fail to empower communities.

Figure 1: Levels of community engagement adapted from WHO (2023) Guidance on engagement of communities and civil society to end tuberculosis.

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 research in Nigeria and Uganda was designed to listen and learn from TB-affected communities - considering the challenges they face and the capacities they bring. Across both countries, LIGHT used participatory approaches to co-create evidence, co-develop recommendations, and support more meaningful community engagement in TB responses.

PHOTOVOICE IN NIGERIA


THE LIGHT CONSORTIUM

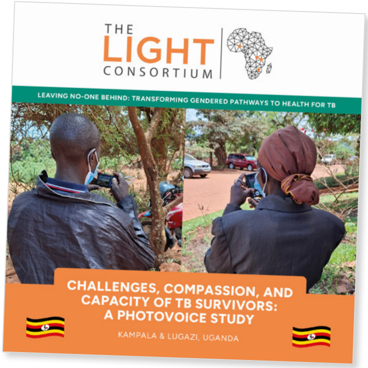
LEAVING NO-ONE BEHIND: TRANSFORMING GENDERED PATHWAYS TO HEALTH FOR TB

GENDER-RESPONSIVE TUBERCULOSIS PREVENTION & CARE: A PHOTOVOICE STUDY

KARU LOCAL GOVERNMENT AREA, NASARAWA STATE, NIGERIA

In Nigeria, LIGHT partner, Zankli Research Center (ZRC), used Photovoice, an arts-based participatory research method that invites individuals to document their daily lives and express their perspectives through photography (Photovoice booklet Nigeria). The study engaged 25 people affected by TB to understand their experiences of TB care and identify priorities and recommendations for action. Participants included 8 people who had received TB treatment, 8 family members who had cared for someone with TB, and 9 healthcare providers working in TB clinics in Masaka and Uke Primary Health Centres in Karu Local Government Area, Nasarawa State, near Abuja.

PHOTOVOICE IN UGANDA


THE LIGHT CONSORTIUM

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

CHALLENGES, COMPASSION, AND CAPACITY OF TB SURVIVORS: A PHOTOVOICE STUDY

KAMPALA & LUGAZI, UGANDA

In Uganda, LIGHT partner, Makerere University Lung Institute (MLI), explored how TB survivors in urban Central Uganda could be more meaningfully included in TB programmes by understanding their lived experiences and preferences for engagement (Photovoice booklet Uganda). The 15 participants were survivors of pulmonary TB, including 8 men and 7 women who had completed treatment between 6 and 36 months before recruitment at Kawolo General Hospital in Lugazi and Naguru National Referral Hospital in Kampala.

THE DESTINE STUDY IN NIGERIA

The DESTINE study[4], led by LIGHT's early-career researcher in Nigeria, applied a mixed-methods design combining participatory, qualitative, and quantitative research approaches to co-create and evaluate a community-based, gender-responsive TB intervention focused on men in a peri-urban setting in Karu Local Government Area near the Federal Capital City of Abuja.

		WHAT DID LIGHT DO?	WHAT IT LED TO
ENGAGEMENT STAGE	**CONSULT**	During the exploratory phase of **DESTINE**, LIGHT conducted interviews and focus group discussions with 36 men who are vulnerable to TB due to their high-risk occupations, such as mining and transport, to better understand how they respond to TB symptoms, when and where they sought health care, and how they navigate fragmented health systems in the peri-urban context.	Generated evidence on men's care-seeking pathways, barriers, and priorities, which informed intervention design.
	INVOLVE	**DESTINE** involved TB stakeholders, survivors, and community leaders in co-creating a community-led TB intervention to reach men and address the masculine norms and barriers hindering their care-seeking. The intervention combined men-led TB awareness campaigns and mobile digital chest X-ray screening in male-dominated congregate settings to reduce the high opportunity costs and stigma associated with TB. All **photovoice** participants were trained in ethical photography and given small digital cameras. Those in Nigeria took photos over a 4-week period to represent their experiences, while participants in Uganda captured their photo stories within two weeks. Participants selected and discussed key photos within the participant group in subsequent workshops.	Ensured that intervention design and research outputs reflected community realities, priorities, and preferences.
	COLLABORATE	During **photovoice** workshops, participants in both countries worked together clustering their photos thematically and synthesising meaning. They reflected on their photo stories and agreed on recommendations for policy and practice. Participants selected their most important photos for a photovoice exhibition and booklet in each country – 33 images in Nigeria and 50 images in Uganda. LIGHT collaborated with influential members in 2 communities selected as **DESTINE** intervention clusters to form Local TB Action Groups (LTAG), made up of influential members of the community such as palace secretaries, TB survivors, commercial tricycle operators, known as *keke napep*, car park leaders, market women leaders, youth leaders, and religious leaders, among others. The LTAG were responsible for leading the planning and implementation of the co-created DESTINE intervention in their communities for 6 months.	Co-developed recommendations and enabled community-led implementation of the intervention.
	EMPOWER	**DESTINE** provided initial training on TB, stigma and community engagement, and LTAGs localised TB messages using cultural music, drama, and dialects beyond the widely spoken Hausa language. They enlisted existing community resources, previously overlooked by many formal programmes, and leveraged trusted knowledge transmission channels, including 'rumour-spreading machinery', and key social events and gatherings to integrate their activities. Pre- and post-intervention household surveys in the intervention and control cluster communities assessed acceptability, feasibility and effectiveness of the DESTINE intervention. **Photovoice** participants played an active role in the dissemination of the research findings. In Nigeria, an enrichment workshop was held where participants showcased their photo stories to policymakers, healthcare managers and other TB stakeholders. In Uganda, TB survivors first presented their exhibition to stakeholders at the district and division level and then to national stakeholders at a joint workshop in Kampala. Photovoice empowered them to see themselves as vital allies in the fight to end TB propose due to their lived experiences. Participants proposed several impactful roles they can play and advocated for the support they needed to make a lasting impact.	Ensured community ownership, built confidence and advocacy skills, and positioned TB-affected communities as credible partners in TB policy and practice.

LIGHT FINDINGS

Our findings from research in Nigeria and Uganda suggest that:

DEPRIVATION AND GENDER INTERSECT CREATING CONDITIONS FOR TB TO THRIVE

- TB survivors fear TB and other diseases can easily spread within peri-urban environments due to prevailing behavioural and structural challenges that are shaped by poverty. Exposure to TB within these precarious living and working conditions are gendered.
- Lack of employment drives men to take up risky jobs where they work in unhygienic conditions and are exposed to numerous health risks.
- Spending long hours in crowded, poorly ventilated public spaces, like betting spots and video halls, using alcohol and tobacco, and having poor cough etiquette contribute to the risk of acquiring TB, especially among men.
- Women worry about exposure to smoke from cooking and waste burning to polluted water from open manholes and flooding; and contaminated food from nearby roadside kitchens and make-shift food vending kiosks.

BARRIERS TO TB CARE ARE STRUCTURAL AND GENDERED

- Challenges that impede TB care-seeking and treatment across countries are multilayered and rooted in the interplay between gendered socio-economic expectations and the structural limitations of the health system[1].
- Men's experiences of TB symptoms, health seeking, and TB care in peri-urban areas in Nigeria are intersectional. Masculinities intersect with other factors such as informality of work, occupation, education, socio-economic status, migration, and family situations to create systemic barriers to TB care among men.
- Many men in peri-urban settlements cannot afford to show TB symptoms due to strict masculine gender expectations and norms – show of strength and pressure to earn income.
- Well-intended official TB information is not tailored to reach men and often includes stigmatising messages. Many men mistrust formal communication channels. Community communication platforms and capacity in peri-urban contexts, including TB survivor storytelling, remain underutilised for driving TB awareness and behaviour change.
- Stigma and discrimination surrounding TB is rampant in marginalised peri-urban communities, increasing their reluctance to seek and access healthcare services.
- When developing symptoms presumptive of TB, many men make pragmatic decisions about healthcare. They prefer informal and private providers to protect their reputation and income as public health systems are seen as feminine.
- Alternative treatment, sought from outside the formal health system, can delay TB care by providing short-term symptom relief.
- Some communities struggle to access healthcare due to poor infrastructure, being cut off from health facilities during the rainy season.

HEALTH SYSTEMS AND TB CARE ARE GENDER BLIND

- Public health systems are ill-equipped to provide effective, person-centred TB care - often hindered by financial, logistical, and operational challenges.
- Female healthcare workers in Nigeria use innovative strategies to engage and retain men in care within gender-blind health systems. Their efforts adapting TB care to the needs of their patients remain both unrecognised and unsupported.

TB LEAVES LASTING SCARS ON THE LUNGS AND LIVES OF TB SURVIVORS

- After cure, TB survivors continue experiencing myriads of physical, emotional, and work challenges[5]. Common symptoms such as breathlessness, physical weakness, and fatigue leave survivors feeling "crippled", affect performance of domestic chores, and disrupt the livelihoods of both women and men. Many worry that they will never be the same again and be exposed to reinfection.
- The emotional toll of TB is enormous. Appetite loss, discrimination, and isolation during TB treatment trigger self-doubt and a dislike of themselves. Many survivors feel devasted about the loss of work and the need to rely on others for help. Some are more optimistic about their recovery, identifying alternative sources of earning and finding renewed purpose through volunteering.
- People with TB experience stigma and discrimination at home, the health centre, and the community. Many are isolated and left to struggle alone without support within their communities.

Photovoice Uganda Training

MANY TB SURVIVORS ARE 'UNOFFICIAL' TB ADVOCATES THAT NEED MORE SUPPORT TO BE EFFECTIVE

- TB survivors feel compelled by their own experiences and want to play an active role in preventing spread of TB and improving the recovery journey of those with TB. However, post-TB complications and fear of stigma can hold them back. Survivors need to confront fears and overcome tendencies to keep illness private in order to become TB champions.
- Many TB survivors are 'unofficial' TB advocates raising TB awareness, promoting healthy behaviours within their social networks and offering emotional support to other people with TB. They also recognise people with a persistent cough within their community and encourage them to seek healthcare; some even go as far as providing transport support.

> *"It is my responsibility to warn people about TB's severity, encourage them to seek hospital care, and offer practical support like transportation to help them access timely treatment."*
>
> **TB survivor 3, male, Kawolo**

TB CARE THAT IS CO-CREATED WITH AFFECTED COMMUNITIES IS ACCEPTABLE AND EFFECTIVE

- When TB care is co-created with and led by trusted and influential local actors within communities, like DESTINE[6], it becomes more acceptable and feasible.
- LTAG's localised TB awareness campaigns in male-dominated congregate settings significantly increased TB knowledge and reduced TB-related stigma, particularly among women, lower-income men, and more educated participants.
- The DESTINE approach significantly improved engagement with care, raising TB notification by 35% in the intervention communities.

LIGHT IMPACT

LIGHT's community-based participatory research **expanded evidence** on gendered experiences of disease, TB care and post-TB consequences and **strengthened the visibility of TB-affected communities within TB policy**. Our research **empowered people affected by TB for advocacy and action** and demonstrated their **capacity for leading service delivery** and the **effectiveness of community-led approaches**. Findings were used to inform district-level action planning as well as national and international policy dialogue and guidelines, contributing to more equitable and people-centred TB care.

CONCEPTUAL IMPACT

EXPANDED EVIDENCE ON TB AMONG MEN AND OTHER KEY POPULATIONS

- DESTINE and photovoice research findings **contributed new insights into the gendered experiences of disease** among men with TB in peri-urban settings and the individual and structural challenges they face in accessing care, reinforcing the WHO and Stop TB Partnership's calls for community-based, gender-responsive TB responses.
- LIGHT research **strengthened the visibility of local innovations and initiatives** by frontline healthcare workers and TB survivors which tend to remain unnoticed and unsupported by gender-blind health systems, calling for their meaningful engagement from planning to implementation and evaluation.


Photovoice Nigeria Enrichment

> *"I am so impressed by the patient engagement concept… I see you (TB survivors) have taken over. This is your thing… You were able to explain why you have taken certain pictures… you own them… I think it is impressive to see you, and how empowered you are. But also the commitment you have protecting the rest of us and moving forward. Thank you very much."*
>
> **Member of the Uganda Community Advisory Group**

INSTRUMENTAL IMPACT

DEMONSTRATED THE EFFECTIVENESS OF COMMUNITY-LED APPROACHES

- DESTINE findings demonstrate that co-created, community-led, gender-responsive TB care – combining men-led TB awareness campaigns and mobile digital chest X-ray screening in male-dominated congregate settings – is **acceptable and feasible**; **increases TB knowledge**; **reduces TB-related stigma**[7]; and **improves engagement with care**.
- Findings from DESTINE study are now informing Nigeria's approach to community engagement and providing evidence for approaches included in the **National TB Strategic Plan 2027-2031**.
- Evidence and recommendations generated by TB survivors in Uganda were shared with the National Tuberculosis and Leprosy Programme, providing evidence for community engagement approaches included in the **National TB and Leprosy Strategic Plan 2025/26 - 2030/31**.
- Photovoice research suggests TB survivors are a **trusted and powerful voice in the community**. Their compelling images and stories made policymakers in Uganda to consider developing a **TB Survivor Strategy** and adding a **community, rights, and gender module** to an online in-service course for healthcare workers on integrated and comprehensive TB and leprosy management.

INSTRUMENTAL IMPACT

> *"I am so privileged to be here. What I noticed from the group [of TB survivors]… taking us through the photos, they appreciated what they are. They have the zeal to fight the disease and take it to another level. They reached a point of saying if we can give them support, they can take the information to other communities that have not been reached. The great information I got from them is that they acknowledge TB is a curable disease, which is a message to us all."*
>
> **District TB Coordinator, Uganda**

CAPACITY STRENGTHENING & ENDURING CONNECTIVITY

STRENGTHENED COLLABORATION BETWEEN TB-AFFECTED COMMUNITIES, RESEARCHERS AND TB PROGRAMMES FOR ADVOCACY AND ACTION

- Community members, including those who served as the LTAG, are key partners in the TB response. Their meaningful engagement in LIGHT ensured that TB-related advocacy and action are **locally led and owned**, positioning them as **sustainable community-based capacity**.
- People affected by TB, who participated in photovoice, gained skills in photography and public speaking, boosted their **confidence**, and felt **being part of the solution**. They continue to use their skills to **protect family and peers against TB**.


Photovoice Nigeria Enrichment

- LIGHT research demonstrated how dialogue between people affected by TB and policymakers can be meaningful, offering **new tools** that can **facilitate discussion** and consensus and **mitigate power imbalances**.

> *"All these pictures are very important, and the Government needs to do more to improve the quality of life for patients and health workers, especially regarding that picture of beautiful health centres without TB drugs and health workers. I will push more to see that something is done about it."*
>
> **Policymaker, male, enrichment workshop, Nigeria**

> *"This [photovoice study] is an eye-opener and sensitisation, especially on the issues of awareness, nutrition, and ventilation… I appreciate the organisers for coming and for giving us an insight on where to concentrate."*
>
> **Healthcare worker, female, enrichment workshop, Nigeria**

- Researchers in Nigeria and Uganda expanded their knowledge and skills in **participatory research methods**. Experiences and critical reflection on their benefits and challenges will help strengthen their **community engagement** in future research proposals and programmes.

LONG-TERM CULTURAL IMPACT

EMPOWERED TB-AFFECTED COMMUNITIES TO BECOME A CRUCIAL AND A TRUSTED PARTNER

- Community members, including LTAG and photovoice participants, continue to **promote positive messages about TB** through their trusted networks and spheres of influence and **encourage care engagement** among hardly reached groups.
- Confidence and skills among LTAG have been boosted to become **trusted voices** and now play **roles on other health** issues most recently human papillomavirus vaccinations for cervical cancer prevention and malaria.

RECOMMENDATIONS

TB-affected communities are lived experience experts and allies in the fight to end TB. Drawing on their expertise, they can be **effective role models and TB Champions** in their communities conducting community education, offering early detection support and peer counselling; and driving TB stigma reduction, campaigns, and outreaches.

Health systems should not simply rely on their passion but provide structured support to make a lasting impact:

- **Knowledge:** Ongoing training on TB transmission, treatment, and prevention to ensure accurate public messaging.
- **Skills:** Development of communication, counselling, and advocacy skills to engage communities effectively.
- **Tools:** Provision of materials (e.g., posters, T-shirts, leaflets) to support outreach and build visibility.
- **Peer Networks:** Strong survivor networks for coordination, emotional support, and shared learning.
- **Health System Integration:** Recognition as partners in national TB programmes, with clear roles and referral pathways.
- **Social Protection:** Prevent catastrophic costs, extend social protection, and offer skills building for TB survivors.
- **Multi-sectoral collaboration and accountability:** Ensure access to safe housing, water, sanitation, and clean cooking.

Photovoice Nigeria Enrichment

Photovoice Uganda Dissemination

CONCLUSION

LIGHT's community work in Nigeria and Uganda shows that **people affected by TB** are not just "beneficiaries" - they are **co-designers, educators, and change agents**. Affected communities should be actively involved as key trusted partners in creating and implementing solutions. Tailored community-led TB messaging and gender-responsive systematic TB screening in the community - particularly reaching men who do not present to clinics - has real potential in reducing TB transmission and deaths among men, women and children.

Photovoice Nigeria Enrichment

REFERENCES

1. Ugwu, C., Kolawole, G., Ringwald, B., Bimba, J., Squire, S. B. and Wingfield, T. (2026) 'Adapting health systems to men's realities: An intersectional exploration of men's barriers to TB care in Nigeria's peri-urban communities', *SSM - Health Systems*, 6, pp. 100188. https://doi.org/10.1016/j.ssmhs.2026.100188
2. Nidoi, J., Pulford, J., Wingfield, T., Rachael, T., Ringwald, B., Katagira, W., Muttamba, W., Nattimba, M., Namuli, Z. and Kirenga, B., 2025. Finding the missing men with tuberculosis: a participatory approach to identify priority interventions in Uganda. *Health Policy and Planning*, 40(1), pp.1-12. https://doi.org/10.1093/heapol/czae087
3. Dodd, P.J. and Horton, K.C., 2026. A global analysis of patterns of tuberculosis exposure and transmission. Proceedings of the National Academy of Sciences, 123(11), p.e2526321123. https://doi.org/10.1073/pnas.2526321123
4. Ugwu, C. (2025) *Doctoral thesis: Development And Evaluation of a Gender Responsive Tuberculosis Intervention for Community Settings in Nigeria (The DESTINE Study)*. https://doi.org/10.57978/2px3-ks59
5. Katagira, W., Ringwald, B., Hamala, R., Ebil, F., Areco, P., Nattimba, M., et al. (2025) Poster: *"You will never be the same": A photovoice study with TB survivors in Uganda.* https://unionconf2025.abstractserver.com/programme/#/details/presentations/385
6. Ugwu, C., Adekeye, O., Ringwald, B., Thomson, R., Chijioke-Akaniro, O., Anyaike, C., Squire, S. B., Bimba, J. and Wingfield, T. (2025) 'Co-creation of a gender responsive TB intervention in Nigeria: a researcher-led collaborative study', *BMC Health Services Research*, 25(1), pp. 63. https://doi.org/10.1186/s12913-025-12241-7
7. Ugwu, C., Aneke, C., Zoakah, N., Bimba, J., Squire, S. B. and Wingfield, T. (2025) *Poster: Assessing the effect of a community-driven, gender-responsive TB initiative on TB-related knowledge and stigma: A controlled before-and-after interventional study in peri-urban communities, Nigeria.* https://unionconf2025.abstractserver.com/programme/#/details/presentations/1354

@LIGHTonTB **@LIGHTonTB** **The LIGHT Consortium** **https://light.lstmed.ac.uk**

Partners: Funder: