

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



PREVENTION & CARE: A PHOTOVOICE STUDY



KARU LOCAL GOVERNMENT AREA, NASARAWA STATE, NIGERIA





Tuberculosis (TB) affected more than 10.6 million\* people worldwide in 2022, primarily those living in poverty and those who are marginalised. TB is an infectious disease that is caused by bacteria, most often affecting the lungs, taking the lives of an estimated 1.3 million\* people globally every year. Although TB can affect anyone, people on the African continent are disproportionally affected, accounting for close to 2.5 million\* new cases of TB and over 300,000\* TB-related deaths annually.

\*WHO Global Tuberculosis Report 2023

#### **TUBERCULOSIS IN NIGERIA**



Nigeria has the highest TB burden in Africa. In 2022, every day, more than 1,230 people developed TB disease and about 410 people died because of TB in Nigeria.\* In line with global trends, most people developing TB disease in Nigeria are men (54%), followed by women (39%) and children (7%).\*

Although Nigeria has made tremendous progress in TB diagnosis and treatment, 2 in 5 people with TB remained undiagnosed and missed out on care in 2022.\*

Delayed diagnosis and disease progression cause worse outcomes including treatment failure, disability, or death, alongside catastrophic economic and social consequences for those with TB and their families. In-depth understanding of the gendered barriers to TB care is often lacking.

This study set out to understand the experience of those affected by TB including people with TB, affected families, and healthcare workers using photovoice to tell their story and to suggest recommendations for action in peri-urban Nigeria.









### This booklet is one of a series of four, with one booklet created for each of the participatory action research studies by LIGHT partners in Nigeria, Kenya, Malawi and Uganda.

LIGHT is a six-year cross-disciplinary global health research programme funded by UK Aid, led by Liverpool School of Tropical Medicine working with partners in Kenya, Malawi, Nigeria, Uganda and the UK. The partners are the African Institute for Development Policy (AFIDEP), Malawi Liverpool Wellcome Programme (MLW), Makerere University Lung Institute (MLI), Respiratory Society of Kenya (ReSoK), Zankli Research Centre (ZRC), London School of Hygiene & Tropical Medicine, and the Liverpool School of Tropical Medicine (LSTM).

















#### **GLOSSARY**

Over 500 languages are spoken in Nigeria. The Nigeria Pidgin language has evolved among people in multi-lingual context combining them all. Here we explain some Nigerian Pidgin phrases for readers who are not familiar with this language.

Almajiri system: Under the Almajiri system, Muslim parents send their children, mostly boys aged 4-12 years, to distant locations to acquire Qur'anic education under the tutorship of a renowned scholar. Almajirai, who can't afford fees, are often forced by their teachers to beg on the streets to fund their Qur'anic education.

**Keke Napep:** Nigerian Pidgin to refer to a tricycle, a common mode of transport across the country.

'Lack of money no fit stop TB treatment, because say treatment dey free':

Nigerian Pidgin for 'Lack of money does not prevent TB treatment because the treatment is free.'

Maza Zumuta: Men's Fellowship (Community of men in the church).

'This na how I dey': Nigerian Pidgin for 'This is how I am.'

'We fit no chop food for house': Nigerian Pidgin for 'There is no food to eat in our house.'

Wiwi: Nigerian Pidgin to refer to Cannabis.



#### **PLACE**

The study took place in the catchment areas of two Primary Health Centres, Masaka and Uke, in Karu Local Government Area. Karu is 1 of 13 Local Government Areas in Nasarawa State, near the Federal Capital City of Abuja. Soaring costs of housing in Abuja have forced people to look for shelter and land outside the capital. As a result, Karu has grown rapidly, beyond its original planned capacity. Many people in Karu face housing problems like crowding, lack of water, and poor sanitation as well as overstretched health facilities. People seeking care at Masaka and Uke Primary Health Centres do not only come from Karu's urban centres but also from nearby rural areas.

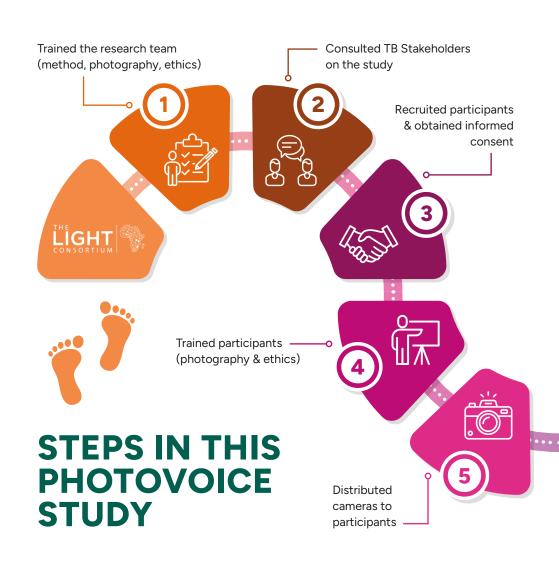


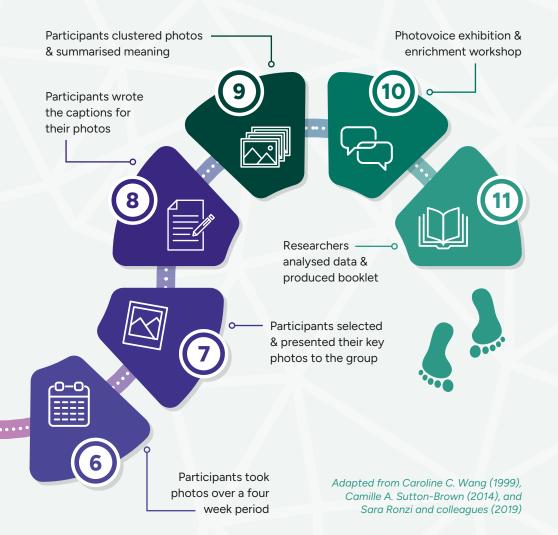
#### **PEOPLE**

Twenty-five participants were affiliated with Masaka and Uke Primary Health Centres, where eight participants received TB treatment; eight were family members caring for a person with TB; and nine participants worked as healthcare providers in the TB clinics. There were 10 women and 15 men whom you will "meet" in the following pages.

#### **PROCESS**

Photovoice is a creative participatory research method, in which people document their everyday lives and express their perspectives through photography. It uses the power of visual narratives to foster understanding and empathy, promote dialogue, and encourage action.







### PEOPLE BEHIND THE LENS



**SAMUEL YAKWARI (48)** 

"I am happy to be part of the study. I have learned from persons with TB about their experiences in accessing TB care and services."



**BAKO TANKO (61)** 

"I'm happy with the photovoice because some areas that have been abandoned in the health centres for a long time has drawn government attention."



#### **FATIMA MUHAMMED (30), STUDENT**

"It was great to be part of the Photovoice project, because it has enlightened so many people on TB especially those in rural area."



#### **BLESSING LIKITA (32)**

"I am also a TB volunteer. I will share my experience with the world on photovoice."



#### **MARGERET OGBOLLE (53), NURSE**

"I'm so happy with the photovoice study because it has enlightened us visually about the challenges our patients face in TB care and services."



**ZAINAB IBRAHIM (28), STUDENT AND TEACHER** 

"I'm very happy with the photovoice because it makes you realize that health is wealth, not wealth is health. It also creates awareness for people to know that TB drugs are free."



#### **ONOJA JOSEPHINE (42), PETTY TRADER**

"I just love photovoice as I can take pictures to express myself."



#### **IBRAHIM SANUSI (23), ROADSIDE MOTOR MECHANIC**

"I thank God for this study and will encourage people to go and get TB medication which is free."



#### **GODDAY SHUAIBU (28), SECURITY GUARD**

"My aunty battled with TB, being and part of this study has helped others have more information on TB."



**IBRAHIM SANUSI** 



**TANKO KYAUTA (48)** 

"I want to sincerely appreciate the photovoice study because since we started this study there have been an increase in TB drugs uptake and we request that the government should create more labs for TB screening."



SETH KAKA (42)

"Photovoice study has helped to create awareness of TB because before now, so many people were not aware of TB and its danger."



**HELEN THOMAS** 



TRYPHOSA FELIX (42), TEACHER

"I appreciate this study because it makes people like me to know that TB is curable and can help others within my community."



**RAHILA MUSA (37), TEACHER** 

"The photovoice study is very educative and reliable."



**ESTHER JAPETH (40), HEALTH CARE WORKER** 

"Photovoice creates an opportunity for change and awareness."



**LUKA BARDE (40), FARMER** 

"The photovoice project has helped me to document my TB experience."



**ABDULLAHI UMAR BALA (38)** 

"Photovoice is a very important way of talking and sharing about TB."



REJOICE NICHOLAS (21), STUDENT AND RESTAURANT CASHIER

"I enjoyed the study because it has created awareness of TB stigmatization."



NAFIU BALA MUHAMMED (36), PASTORALIST

"The study was fun, as being part of it, makes me realise the need to help more people, especially men on TB education."



**JOSEPH RABO DOGARA (35)** 

"I love photovoice. It makes me feel like I am part of the solution."



**AMOS GONI (45), FURNITURE CARPENTER** 

"The photovoice will help people to take TB care seriously."



**SALISU MUSA** 



**KASIMU DAUDA (55), BUSINESSMAN** 

"I am happy to be part of the study because I can contribute in ending TB using pictures."



#### **EZEKIAL BAKO (39), LOCAL MASON**

"The experience I got from the photovoice study is nice, and I urge the government to please try and create a dot center in Karu so that we won't have to go that far to get TB drugs."



# GENDER DIFFERENCES IN LIVING AND WORKING ENVIRONMENTS WHERE TB THRIVES

Participants illustrated and narrated how the precarious living and working conditions in Karu affect health and expose people to TB. Poor sanitation and waste management bring about ill-health and increase vulnerability to TB. Men's vulnerability was highlighted in the photos. Lack of employment drives men to take up dangerous jobs where they work in unhygienic conditions and are exposed to numerous health risks. Many men also spend long hours in poorly ventilated public spaces, like video halls, and have unhealthy behaviours like smoking and harmful alcohol use. Participants also reflected on hardships faced by children, mostly boys, living away from their families to acquire Qur'anic education in Karu. As a result of this education system, known as Almajiri, children are vulnerable to homelessness and lack of healthcare.





"In rural areas like ours, there is inadequate waste management practices which can increase the spread of TB. Poor sanitation and waste disposal can create environments conducive for the transmission of TB bacteria."

Family member, female, Masaka

"Waste management and improved sanitation infrastructure are needed in reducing the spread of TB in our communities."

Family member, female, Masaka

"This picture of a person using a wheelbarrow for dumpsite packing showing the occupational hazards faced by workers in unhygienic environments. Proper waste management practices are crucial to prevent health risks, especially for TB patients. This person does dumpsite packing for a living and they do not do it hygienically, which is detrimental to their health."

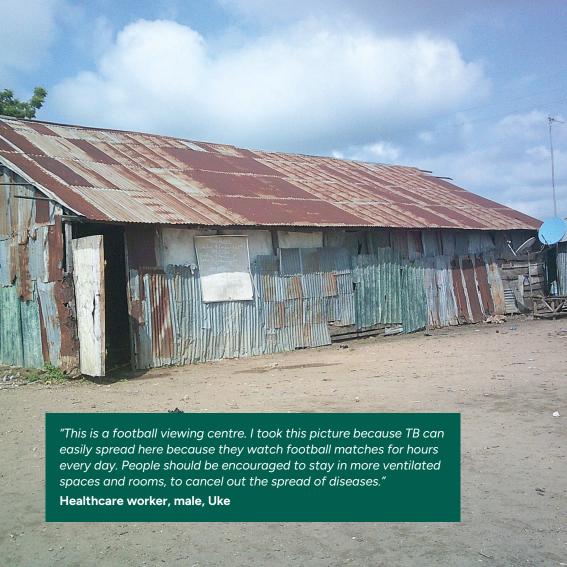
Healthcare worker, male, Masaka





"The dumpsite serves as a source of income for some, including people with TB, due to limited job opportunities. However, this practice is unhygienic and places them at health risks, there is need for alternative livelihoods and better waste management."

Healthcare worker, male, Masaka





The Almajiri system: "This is a picture of homeless children who walk about in groups and live in groups. Is an easy way of spreading disease. Government needs to address this as they don't have access to health care and have the potential to infect others with TB."

#### TB survivor, female, Uke

"This picture of a person smoking "wiwi" (Cannabis) raises concerns about TB management. Smoking and other poor health behaviours increase the risk of contracting TB."

Healthcare worker, male, Masaka





# STIGMA AND DISCRIMINATION AGAINST MEN AND WOMEN WITH TB

Stigma and discrimination surrounding TB can significantly impact marginalised peri-urban communities, increasing their reluctance to seek and access healthcare services. Participants emphasise the need for stigma-free TB communication and awareness, highlighting important sources of accurate TB information. Whilst well-intended, health education often includes stigmatising messages.

As a result, people with TB can experience stigma and discrimination at home, the health centre, and the community. For example, when utensils are separated, and individuals or entire families are isolated. More stigma-reduction TB awareness campaigns are needed to end TB stigma. Male-specific campaigns delivered in places where men congregate could help men overcome reluctance and improve access to TB care.





"Radio and TV stations na important things, na where we dey get information on TB."

Family member, female, Masaka





"A wife with TB is told to isolate herself from her husband and children, so she will not infect the rest of the family. When she goes to the market, no one is willing to sell to her. In some communities, the discrimination is high to the extent that the entire family is isolated."

TB survivor, male, Masaka

"This is a picture of a family eating together in the same plate. I took this picture to show that we should not stigmatise people living with TB. As long as people with TB take their medication properly, their families cannot contract TB. There should be more awareness on eradicating stigma for people living with TB with continuous awareness many people will know more about TB."

TB survivor, male, Masaka





"This TB poster shows two women - one with a dry cough and the other with a wet cough - covering their mouths. The problem here is that showing two women coughing increases stigma for women."

Healthcare worker, male, Masaka



## GENDERED BARRIERS TO TB CARE AND TREATMENT

Participants illustrated and narrated the various challenges that hold people back from accessing TB services and following treatment regimens. Some communities struggle to access healthcare due to **poor infrastructure**, being cut off from health facilities during the rainy season.

Economic challenges are widespread and impact access to healthcare. Many people cannot afford to buy basic face masks required to enter health facilities.

Most men, like *Keke Napep* drivers, cannot afford to take time off work as they risk losing income or employment when they go to the health facility. **Alternative treatment**, sought from outside the formal health system, can delay care seeking for TB symptoms. **Water and nutrition** are essential for people with TB to take their medication and follow their treatment schedule. Family members illustrated that it was challenging for them to afford clean water and a healthy diet in Karu.



"This borehole is privately owned. For TB survivors like my child, access to clean water is not just a convenience but a necessity to prevent dehydration and support recovery. This borehole is publicly available, but it is owned by private individuals who sell the water."

#### Family member, female, Masaka



"The cost of buying nose masks is a challenge to the people. It is encouraged that everyone visiting health centres wears nose masks."

Healthcare worker, female, Uke





"This is a picture of tree trunks and barks that native doctors give out to people who are ill. The native doctors play a major role in discouraging TB patients and people from going to the primary healthcare centres and that is challenging. The use of traditional medicine is a remedy passed down through generations."

Family member, male, Uke









"TB patients need more calories to combat the disease and the weight loss, yet access to a balanced diet is very difficult as they end up eating junk. It is not easy for us as a family member to maintain a healthy diet of a family member who has TB, because they eat more and more."

Family member, male, Masaka



#### HEALTH SYSTEMS CHALLENGES AND ENABLERS

The health system's ability to provide effective TB care is often hindered by financial, logistical, and operational challenges. Photos and narratives by the participants highlight the success stories and challenges of the health system in providing quality TB care. While the health infrastructure is conducive, many facilities are underfunded lacking trained personnel and essential resources. Health products are effective in preventing and treating TB. For example, face masks and hand gloves protect healthcare workers during their work in the TB clinic. Moreover, TB treatment and drugs are free of charge, but this is not well-known in the community. The **outdated health information system** is conducive for producing errors, like missed records, incomplete reports, and delayed requests for drugs and commodities, which contribute to **frequent stock-outs** at the primary health centres. Together, these challenges undermine the effectiveness and quality of TB care in Karu.





"Fine hospital, small number of doctors but plenty patients."

Healthcare worker, female, Masaka

"A clean, conducive, and well-ventilated hospital environment encourages patients to attend clinics and hospital visits, promoting better health outcomes for TB."

Healthcare worker, male, Masaka

"Disposable hand gloves are essential for carrying samples to prevent contamination. However, the availability of gloves and other consumables is often limited in healthcare facilities."

Healthcare worker, male, Masaka







"Proper use of face masks is crucial for healthcare workers and patients to prevent the spread of TB. The TB drugs in the picture are provided free by the government."

Healthcare worker, male, Masaka

"Lack of money no fit stop TB treatment, because say treatment dey free but people don't know." Family member, male, Uke



"As a HCW (healthcare worker), we always run out of cartridges in the facility for up to a month. This picture shows the last one left at that time, and I have called both state and national programme office because they went out of stock 2 weeks ago, but nothing was done about it. Lack of healthcare services is such a big problem when it comes to dealing with TB. The problem is that the facility delays in informing the state or national on time."

Healthcare worker, female, Uke





"This is the card room, also known as the record room, which demonstrates the traditional method of keeping patient files organised. In today's digital age, we need to shift to electronic health records (EHR) which offers a more efficient and secure way to manage patient information, reducing the risk of missing files or folders."

Healthcare worker, female, Masaka

# RECOMMENDATIONS OF ACTIONS FOR CHANGE

## FROM PEOPLE AFFECTED BY TUBERCULOSIS

#### **HEALTH SECTOR**





- Offer comprehensive, gender-responsive support for women and men with TB and their families.
- Provide nutritional support and resources to people with TB from low-income households.



#### **HEALTH PRODUCT**

• Offer affordable face masks to all people visiting health centres.

#### **LEADERSHIP & GOVERNANCE**



- Integrate TB services into general healthcare.
- Collaborate with the Departments of Environment; Works; Labour & Employment to address precarious working conditions of men.
- Improve the supply chain for essential drugs and consumables.



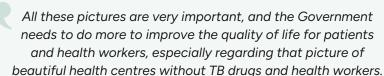
#### **HEALTH WORKFORCE**

- Increase the healthcare workforce for TB.
- Train healthcare workers on gender-responsive TB care.



#### **HEALTH INFORMATION SYSTEM**

 Introduce a robust inventory management system and electronic health records.



I will push more to see that something is done about it.

Policymaker, male, enrichment workshop





- Provide gender-specific stigma-free health education & information.
- Collaborate with the Department of Information and Media to increase TB awareness and reduce TB stigma.
- Engage communities, religious leaders, traditional healers, and drug vendors for male-specific TB campaigns.





To address the Almajiri system and reduce the spread of TB among children, the Government should provide healthcare, education, and shelter for homeless children.

Policymaker, male, enrichment workshop

#### **OTHER SECTORS**

- Ensure access to nutritious food and clean water for everyone.
- Improve road infrastructure to ensure access to healthcare throughout the year.
- Establish proper waste management systems and practices.



- Supply protective gear and training to waste workers to prevent health risks.
- Implement anti-discrimination laws and strengthen the rights of workers in the informal economy.
- Address the Almajiri system by providing healthcare, education, and shelter for homeless children.

We, the women, will continue to support our young boys and men to get tested so that they don't infect the family, so that they will have a culture of getting tested if they have symptoms.

Cultural leader, female, enrichment workshop

## REFLECTIONS ON PHOTOVOICE

## FROM PEOPLE WORKING TO END TUBERCULOSIS

"Photovoice is a basic method of research yet underused in Nigeria. It has the potential to bring about positive change and is relevant to a wide range of issues."

TB stakeholder, photovoice sensitisation meeting

"Photovoice is a powerful communication tool. Photographs are visual representations and can effectively communicate messages without relying solely on language. Photovoice can help us overcome language barriers in TB control efforts."

TB stakeholder, photovoice sensitisation meeting

"Photovoice should be replicated by other organizations in the public health field. If we expand the reach of Photovoice, we can maximise its potential impact on TB control."

TB stakeholder, photovoice sensitisation meeting

"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, photovoice exhibition, Nigeria

The Photovoice pictures should be displayed in the organisation (national TB programme) to promote awareness and appreciate the participants' work.

A screen display of the photographs would allow staff, visitors, and stakeholders to view the visual narratives and engage with the stories behind the images.

TB stakeholder, photovoice sensitisation meeting





# **ACKNOWLEDGEMENTS**

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## For further information, please see:



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