

# COUNTDOWN

Calling time on Neglected Tropical Diseases

LSTM  
LIVERPOOL SCHOOL  
OF TROPICAL MEDICINE



## Stories of living with neglected tropical diseases (NTDs) affecting the skin- a special photography exhibition in Nigeria

*Stories of people living with skin NTDs and their caregivers have been captured at a special photography exhibition in Nigeria. A photovoice study, forming part of the COUNTDOWN Wellbeing research project, demonstrates the impact NTDs can have socially and psychologically on people affected and their caregivers. It emphasises the importance of learning from those affected, amplifying their voices and supporting positive change against the stigma they can face in their communities. As a result of these findings support groups have been established to bring together people affected by skin NTDs with the aim of addressing treatment, psychological wellbeing and vocational training, as well as creating a space to build networks.*



### People living with skin NTDs share their stories

As part of the COUNTDOWN Wellbeing research project, people affected by NTDs and their caregivers were recruited as co-researchers in Kwara and Kaduna states.

The co-researchers were trained in Photovoice methodology, specifically to use photography to share their experiences of living with skin conditions such as leprosy, Buruli ulcer, lymphedema, and hydrocele.

The photos were then shared in the special photography exhibition in Nigeria. The exhibition emphasised the stigma that is often faced by people with these conditions, and the social and mental burden that this can place on them and their caregivers.

In addition to the photo exhibition, Skin Stories photo booklets have been created, which present the findings of the photovoice activity. They have been separated into themes identified in partnership with participants, including impacts on functioning, stigma, psychological wellbeing and support, and they show the realities of people affected by NTDs through their lens. The Skin Stories booklets were this year's recipient of the [ISNTD Festival 2021 Photo Award](#). You can see more of the photos from the Wellbeing project by downloading the [Kwara photo booklet](#) and the [Kaduna photo booklet](#).

The use of photovoice fostered the uptake of research findings into NTD interventions and programme planning responsive to priorities, such as trainings, identifying patient advocates, social mobilization teams and support groups. The project is now taking these findings further by involving people with NTDs in leading and shaping a series of support groups, with the support of State NTD programme implementers.

These groups bring people affected by NTDs together, providing a positive environment where they can receive peer support and build networks. The groups address issues raised from the research, providing guidance on areas such as disease management, vocational training and psychosocial support.

Tosin Adekeye, a Research Analyst at Sightsavers, said: *“It is really exciting to see the people affected as co-researchers driving the support groups, deciding when and where they will meet, and setting the agenda for their meeting.”*

The initiative, in collaboration with the Nigerian Federal Ministry of Health (FMoH), Kaduna and Kwara States Ministry of Health and the Local Government Departments of Health, is being implemented by Sightsavers in partnership with the Liverpool School of Tropical Medicine (LSTM), as part of the Wellbeing project within the COUNTDOWN research programme.

## Showing the impact of skin NTDs

The photos at the exhibition show the devastating impact that NTDs affecting the skin can have, both for those affected and for their caregivers.

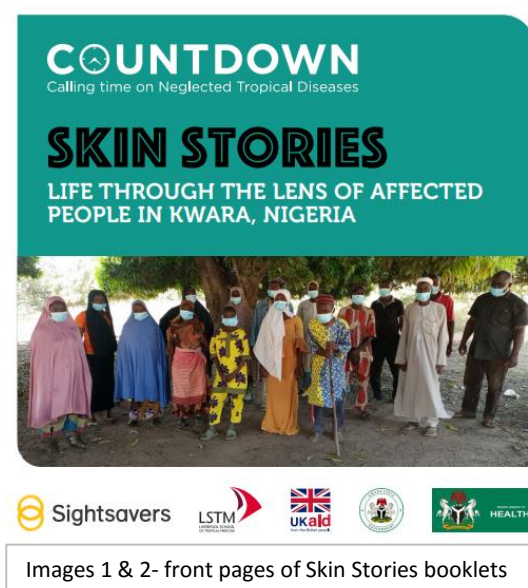
Abdulmimini Hussain, a participant with leprosy, writes that *“we are not allowed to live where the other healthy people stay, and I am not happy seeing that we are separated from the others.”*

Other participants described losing their livelihoods as a result of their illness. *“I took this photo because of my ill health,”* explains Saidu Isah, who is living with leprosy. *“I am idle without a trade or any activity to keep me busy, it shows that I beg for alms to earn a living.”*

Participants also mentioned the support they received from family, friends and others in their community.

According to David Irimiya, who has lymphedema, *“[My wife] takes very good care of me. Whenever I am unable to go to the farm as a result of ill health, she takes up the responsibility of working on the farm.”*

These accounts have left a strong impression for those who have been involved in the project.



Images 1 & 2- front pages of Skin Stories booklets

***“Photovoice research has opened my eyes to the plights and yearnings of people with stigmatizing skin diseases such as hydrocele (swollen scrotum), lymphatic filariasis / elephantiasis (swollen leg), leprosy, and Buruli ulcer in society.”***

**Afolayan Olatunde James, Desk Officer at the Kwara State Ministry of Health.**

## “We have to learn from those who are affected”

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The study made use of a community based participatory research approach. This involved using photovoice, where members of the community affected by skin NTDs were trained and supported to take photos to record their experiences in words and pictures.

The photovoice process was used to identify challenges, and promote collective action so that people affected can begin to address these challenges. Some recent COUNTDOWN blog posts provide more information about the photovoice process- [‘The Virtue of Virtual Training: Reflections on Photovoice’](#) and [‘There is a story behind every picture’: Photovoice training and data collection amidst COVID-19.](#)



Image 3- Kwara Skin Stories banner at the exhibition

Photovoice methodology provides a way for local communities to take an active role in shaping research projects. According to Adekeye, *“We can’t see ourselves as the all-knowing researchers; instead, we have to learn from those who are affected.”*

Shahreen Chowdhury at [LSTM](#) added: *“This project has highlighted how powerful photovoice can be in amplifying the voices of people affected through sharing their own stories, but also in taking ownership by leading and actioning positive change.”*

## Supporting positive change

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Support groups have been established in Kwara and Kaduna states and provide guidance on areas such as wound care, treatment, and psychological wellbeing. The idea is that the support groups will gather momentum and that the affected people will continue to meet after the research project ends. It is also hoped that the groups will gain new members and continue to evolve to meet the support needs of persons affected.

Co-researchers will continue using photovoice as the support groups are implemented, in order to document the process.

The project also looks at the wellbeing of the participants before and after the series of support group meetings to determine the impact the support groups have had on stigma reduction and psycho-social wellbeing. *“Our hope is that the groups will have a positive impact on these people’s lives, by improving their wellbeing and reducing the amount of stigma that they experience,”* says Adekeye.

The Wellbeing initiative is taking place alongside other projects as part of the COUNTDOWN programme, which aims to find cost-effective and sustainable ways to control and eliminate the most common NTDs. Funded by [UKAID](#), the programme is operating in several African countries including Nigeria, Liberia, Cameroon and Ghana.

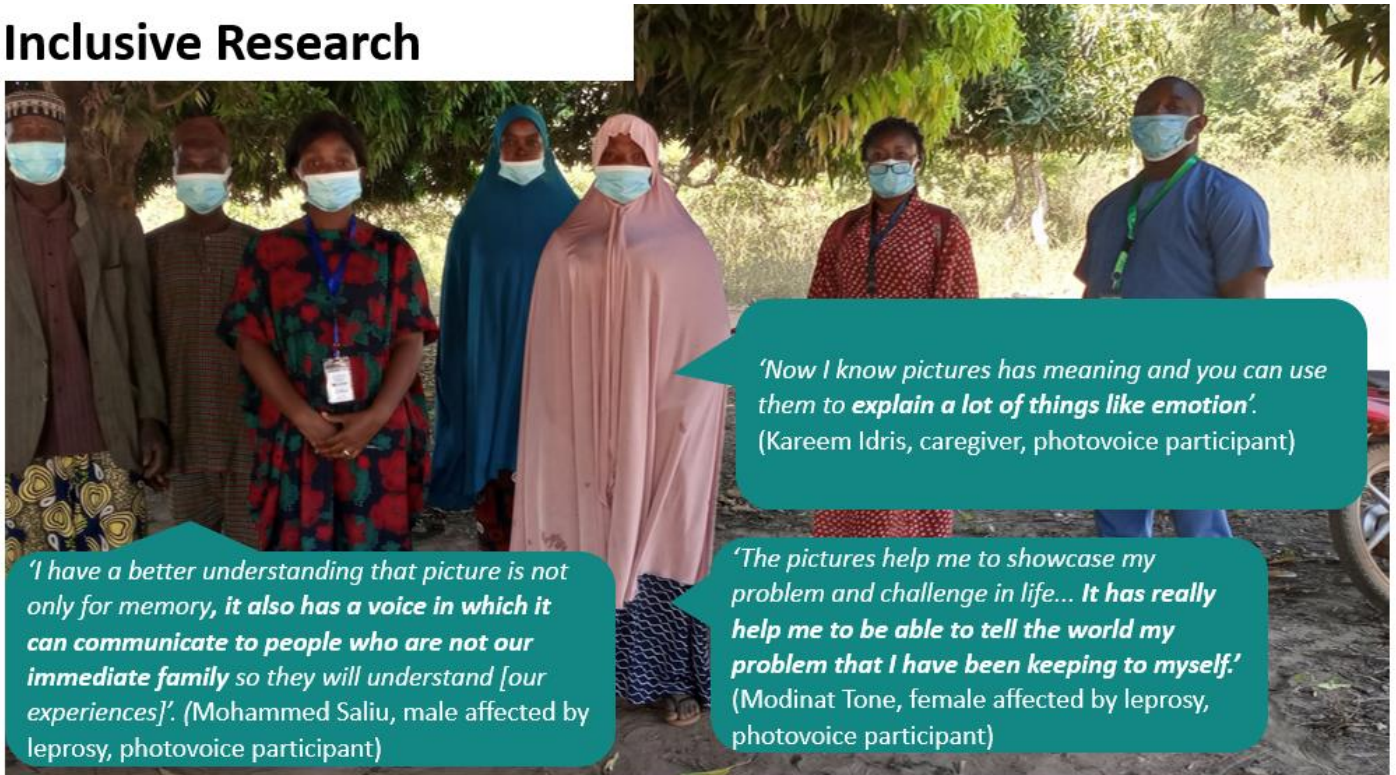
The programme is led by the [Liverpool School of Tropical Medicine \(LSTM\)](#), with support from partners including Sightsavers, [FHI360](#) and government agencies in the host countries.



## Key messages

- Images can be powerful - recognised beyond literacy levels, culture & language.
- Encourage interactions between non-researchers and researchers & reach wider audiences.
- Amplify voices of people involved with/impacted by research, so that researchers & funders can learn from their experiences & prioritise their needs.
- Can situate co-researchers as active agents for social change.
- Create ownership and honour local knowledge.

## Inclusive Research



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