COUNTDOWN Calling time on Neglected Tropical Diseases

SKIN STORIES LIFE THROUGH THE LENS OF AFFECTED PEOPLE IN KADUNA, NIGERIA



















INTRODUCTION

Neglected Tropical Diseases (NTDs) affect around one billion people globally who are often the most poor and marginalised groups in society. Nigeria carries around 25 per cent of Africa's NTD burden. NTDs affecting the skin (for example Buruli Ulcer) often lead to long-term functional limitations and disability, significantly affecting health and wellbeing. Associated stigma can also have disabling impacts through restrictions in livelihood activities, participation and social interactions. Despite these significant impacts, the long-term health and psycho-social needs of persons affected by NTDs are often overlooked in integrated NTD programme design and research. In this project, we sought to understand the day to day experiences of people affected by NTDs and their caregivers through photovoice.

Photovoice is a creative participatory method, which aims to empower participants to tell their own story. Over the course of two weeks, people affected by NTDs and their caregivers took photographs within their communities to capture their experiences. The process involved training of photovoice participants on the use of cameras and ethics of photography. Co-researchers who were people affected by NTDs were recruited as part of the research team to train and support other affected persons within their communities to become photovoice participants. After the two weeks of photo-taking, participants came together to discuss their photographs and experiences and cluster them into themes.

This booklet presents the findings of the photovoice activity. The booklet is separated into themes identified in partnership with participants, including impacts on functioning, stigma, psychological wellbeing and support. These photos will be presented in stakeholder meetings to inform the co-design and implementation of support groups, in partnership with affected persons, caregivers and programme implementers. We aim to show the realities of people affected by NTDs through their lens.

This project took place in Lere, a purposively selected Local Government Area (LGA) in Kaduna State, Nigeria.

BEHIND THE LENS PHOTOVOICE PARTICIPANTS







My name is David Irimiya. I am 32 years old, married to a wife and have two beautiful children. I have been a committed choir member of my church it's a place I love to be because other members of the choir accept me and sometimes come to assist me in the farm. I live at Werre village, Yar Kasuwa, in Lere LGA. I was a farmer alongside my wife but because of my ill health (lymphedema) I can't farm again, my wife just engages in little farming around the house.



Hajara Ibrahim is my name, I am about forty years, married and have 7 children. I live at Dan-alhaji Gabas. I am affected by lymphedema. I used to sell rice before and now I join with the rice mill in our community and sift rice for a fee so as to take care of my family.



I am Ga'aje Saleh. I am 25 years old and married to Mallam Saleh, we have two children. I am a fulltime housewife. I am affected by leprosy. I live at Kawo Kayarda in Lere LGA Kaduna.



My name is Istifanus Aidu. I am over 80 years old, a father of 5 children and so many grandchildren. I live at Kurosha with my son he takes care of me. I am affected by leprosy. I don't do anything except sometimes I help my son pour water on the blocks he makes.



My name is Alhassan Musa. I am 30 years and I live at Dan-alhaji, close to the primary school. I owned a provision store to take care of my family. I am affected by lymphedema. However, after taking the pictures and the conversations I had with you I thought of something else that I could do for myself and now I also sell fuel in jerry cans to further take care of myself and my family. I am married with six children.



My name is Ayuba Abigail. I am 25 years, a student at the School of Health Technology Makarfi and I am also Mama's caregiver who is affected by leprosy. We live at Ladi Maigamo and sometimes I engage in small businesses when at home. I am single and hard working.



I am Zaiya Nuhu. I am 57 years, a mother of 6 children and a housewife. I don't do anything because of my handicapped hands due to leprosy, I just sit around and watch unlike before when I was a petty trader. I live at Kayarda with my husband and children.



My name is Abdullahi Musa. I live at Dan Jaba in Lere LGA. I am married with seven children. I engage in farming mostly sugar cane and maize. I am 50 years of age and I am affected by hydrocele.



My name is Saidu Isah. I live in Chikin Gari Saminaka, Lere LGA, of Kaduna state and am about 55-years. I used to be a farmer before I became handicapped by leprosy, I planted rice and maize. My wife died of childbirth and I have not had another wife since then, this is due to financial difficulty in re-marriage and the fact that my condition makes women not want to marry me. I do not have children and I live with my relatives.



My name is Solomon Aidu, I am 40 years I have 5 children and am a community Leader in Kurosha here in Lere LGA. I am Baba's (Istifanus Aidu) care giver who is affected by leprosy.



My name is Magaji Isiyaku. I live at Chikin Gari here in Saminaka. I am 35 years and married with 3 children. Among other things I take care of Baba Saidu Isa (affected by leprosy) and I sell carpentry materials like wood.



I am Adamu Saleh, I am 45 years married and have 7 children. I live with my family at Kayarda. I do petty business and am also a tailor. I am the primary caregiver of my wife who is affected with leprosy.



I am Mohammed Tanko and I am affected with lymphedema. I am 41 years old, I am married with 6 children. I reside at Hayin Gada Saminaka Lere local Government with family, and my mother and wife, who offer me support.



I am Aliyu Yusuf. I am 25-years and I live at Nasarrawa Saminaka. I am married with two kids, I do not have any form of occupation that I'm engaged in now because of the wound on my leg (due to Buruli ulcer). I used to do Okada (motorcycle) transport but had to stop due to my health condition. When you first came, I was checked by the health worker and asked to go for a test so that I can be adequately treated, I am grateful that you coming has made this happen.

PHYSICAL FUNCTIONING AND PAIN



THEME SUMMARY

Participants described physical impacts that affected their day-to-day functioning and ability to take part in work or activities in the community, sometimes leading to feelings of sadness. Pain and discomfort hindered participants from being able to undertake activities they were able to do prior to their illness. Some participants photographed ways they managed pain in the way they sit or move.



They are thrashing rice. This kind of work can only be done by a healthy person, an unhealthy person like me cannot do this kind of work even though I would like to do it...it shows the inability I have to do normal work...looking at them working, I am excited but I don't feel happy because my ailment does not give a chance to do things like this.

Shuaibu Abdulkadir (Younger male affected by Lymphedema)



This is a spoon; I cannot use it again to eat because my fingers are gone.

I knew how to de-husk this maize before and I did it a lot but now I can only look at people do it I don't have the ability to do it again.

This is firewood; I used to break this with my hands but now I can't.

I used to use this mortar before to pound but now I cannot, and it makes me sad and feel handicapped sometimes I just cry.

Zaiya Nuhu (Older female affected by Leprosy)



This is me with a kettle... I was making ablution but unfortunately, I couldn't stand up and this has always been my challenge with this ailment when I squat or sit in the room or toilet, I find it difficult to stand up sometimes I have to crawl on the ground because of this ailment. My thighs, my back all just ache.

This is my leg. I took this photo because of the state of my legs. In the first place when this leg starts to ache it comes with a fever and cold and I dare not put the legs down or come down from the bed it feels like am been pierced with needles. I feel like a heavy stone is tied to my thighs, when this fever starts it then comes down to the leg and begins to swell and peel like you are peeling cassava. This is what I have been suffering...I feel so much pain and chills.

Hajara Ibrahim

(Younger female affected by Lymphedema)









This is a log of wood. When I begin to feel sick my body just feels dry and stays stiff like this log of wood and I just feel restless and my body lifeless, like this.

Rebecca Ayuba, co-researcher

(Older female affected by Leprosy)

When the pain from my leg increases this is how I sit down and sometimes it eases the pain, unlike how other people sit.

David Irimiya (Younger male affected by Lymphedema)

IMPACT ON SOURCE OF INCOME AND LIVELIHOODS



THEME SUMMARY

Impact on income and livelihood was significant for all participants. This was often in relation to loss of livelihoods as well as having to sell livestock or crops in order to pay hospital bills or to purchase medicines to treat their ailments. Aliyu Yusuf (a young man) affected by Buruli ulcer gave the example of selling his chickens to pay for medicine. The financial burden of caregivers was depicted by both male and female caregivers whereby most of their finances were used in caring for their relatives, and therefore they were unable to complete studies, repair dilapidated houses or restock their shops. However, some participants described adaptation, innovation and resilience in continuing to support themselves economically. Balele Yusuf, a male participant affected by hydrocele expressed his pride in being able to hunt and provide for himself and Mariamu David described her innovation in charcoal production to be able to support her husband.

These are sheep, I had them many before but now I have only two remaining because of my health I sold them all to buy medicine and take care of myself.

Rebecca Ayuba, co-researcher

(Older female affected by Leprosy)

These chickens have been a source of income to me in time when I had nothing and my ailment would not permit me to get any menials job that pays, I sell them to pay for medicine and hospital bills.

Aliyu Yusuf

(Younger male affected with Buruli Ulcer)





This is a charcoal...When my husband's foot began aching, we didn't have anything to sell, this is what I then started selling to get money to take care of us.

Mariamu David

(Female caregiver of David Irimiya, a person affected by Lymphedema)





When my extended family refuse to help because they think I am lazy and making excuses, I hunt so to raise income to care for my ailment. This is better for me than sitting idle...I feel good in the inside when I hunt and sell these animals. It is better for me than sit in one place or begging for assistance.

(Younger male affected by Hydrocele)



I took this photo because of my ill health. I am idle without a trade or any activity to keep me busy, it shows that I beg for alms to earn a living. I do not belong to any group and I do not have a trade of my own.

Saidu Isah (Older male affected by Leprosy)



This is my business I used to sell rice but now...I don't sell again because this sickness has devoured everything, and I don't have money again to sell them.

Hajara Ibrahim

(Younger female affected by Lymphedema)





This is my grinding machine, it used to be a source of income for me and my family, but I could not maintain it because the money that was generated from it had to go into my husband's medical bill. It has now been abandoned because I don't have the financial strength to fix it.

Mariamu David

(Female caregiver of David Irimiya, a person affected by Lymphedema)

This is a photo of the shop I used to have but now the goods in it have been sold, the profit and capital have been used to finance medical care for treatment of my uncle and family. I cannot restock the shop; the sight of it really makes me unhappy.

Magaji Isiyaku

(Caregiver of Saidu Isah, a person affected by Leprosy)





This hut reminds me of the many livestock we use to have. This is where we keep them at night, but it is empty now because we had to sell everything to be able to take baba to the hospital for medical care.

Bello Abdullahi

(Male caregiver of Shuaibu AbdulKadir, a person affected with Lymphedema)



I can no longer go to the market to trade, and this makes me feel unhappy when the thoughts come in that I can't go to buy or sell because I am to care for a sick brother.

This photo of books show my inability to study or school due to me being the one to look after my brother.

Yusuf Zango

(Caregiver of Tanko Mohammed, a person affected by Lymphedema)



STIGMA



THEME SUMMARY

Stigma was often deeply felt and experienced by participants across gender and disease. Internal stigma was depicted whereby young men affected by Lymphedema and Buruli Ulcer reported feelings relating to feeling useless, broken, shame, and sadness because of enlarged legs or obvious wounds. Experiences of external stigma were also captured, ranging from avoidance and rejection from family members and open show(s) of irritation from people in the community. Stigma has resulted in participants withdrawing from society and living in isolation, as reported among men affected by lymphedema and leprosy. Stigma was always described as leading to feelings of sadness and isolation.

INTERNAL STIGMA

The photo reflects how my leg looks like when swollen, the sight of it makes me feel bad that I must be living with my leg like this dried tree.

David Irimiya

(Younger male affected by Lymphedema)

This photo is of a rusted plate that nobody would like to use. It has no use; with this ailment I sometimes feel I don't have use to my family. No one would like to see his body spoiled to this state only if there is no way out. It represents how my health condition is.

Shuaibu Abdulkadir, co-researcher

(Younger male affected by Lymphedema)

This photo of this table represents how I had felt when I start suffering with my leg, looking at it reminded me of the pain and how I felt incomplete, I feel a better part of me is missing that can never be replaced, this makes me feel sad and depressed seeing how my body is infected with this ailment.

Tanko Mohammed

(Younger person affected with Lymphedema)



EXTERNAL STIGMA

This photo shows the long route Baba needs to walk to avoid stigmatization on the shorter route. In our community, Baba suffers stigmatization and so he ensures he takes the road where he will meet with less people....I do not feel good about the way he is being treated in the community. Despite the pain he undergoes due to the sickness, he still suffers stigmatization from the people around. I wish I had a better job; I would have been the sole benefactor of the family so Baba would not have to go out to beg for alms. He does not feel good about the way he is being treated in the community.

Abdullahi Musa

(Older male affected by Leprosy)



I now can no longer go to the field because of my health and I feel bad. I want to be treated so that I can be able to go back to join others to football at the field to exercise and train like I did before now. I used to go and watch but I stopped... when I started going people move away from me, some manage to stay few minutes for us to greet and ask about my health then they move and stay in a different place. I have stopped going there and just stay at home. I am sincerely not happy with how I cannot exercise my body. Because I cannot play ball again and cannot go to my friends or team mates. When I get help I will mingle with people like before and do things with people when I am assisted.

Aliyu Yusuf

(Younger male affected by Buruli Ulcer)



This shoe if I keep it at my door, because of my ailment no one will wear it and that hurts me. Before someone will pick it like when you keep a shoe at the door, someone will admire it and want to wear it to the toilet or so, but no one does that now because people are afraid to contract the disease...that hurts me.

Hajara Ibrahim (Female affected by Lymphedema)

I took this photo because of what disturbs me I have been separated with my family by other family members and was given a different room away from everyone, I am not allowed to sit in their midst and have conversations or be involved in discussions. They only talk to me from afar all because of my ailment...I want to be assisted with medicine that will treat me so that I can return to my family.

Aliyu Yusuf

(Younger male affected by Buruli Ulcer)





This plant always remind me of what a friend once told me. He said that they called the plant Elephant ears and my disease is called elephantiasis, that always reminds him of my condition therefore he does not want to be my friend so that I will not infect him with the disease.

David Irimiya

(Younger male affected by Lymphedema)

OUALITY OF HEALTHCARE



THEME SUMMARY

Quality of healthcare emerged as a key theme as participants mostly shared positive experiences of accessing healthcare. Participants highlighted receiving good guality of care, in reference to close proximity and availability of health centres, and trust and gratitude in health care providers. Chemists, pharmacists or private providers in the community that people knew were particularly important. Alhassan Musa, a younger man affected with lymphedema mentioned appreciating his doctor for treating him kindly with respect while Jamila Sallihu, a female caregiver mentioned that the chemist is well known to them and even offers medicines on credit if she unable to pay for them. However, this was not the case for everyone, as Tanko Mohammed, a young man affected by lymphedema mentioned challenges in affording healthcare and resorting to treat himself at home. Being able to manage pain and discomfort guickly through healthcare providers who were close to the community was critically important to all participants.

This is a health clinic with proximity to me therefore I have easy access to it whenever I need medical care.

David Irimiya

(Younger male affected with Lymphedema)







This is the Chemist that helps me with the medicine I use, they wash and clean my legs, so I took the photo to show the doctors our care givers and tell them my problems.

Aliyu Yusuf (Younger male affected by Buruli Ulcer)

This is the clinic where I seek medical care which is approximately ten minutes walk from my house. Am so glad that I don't have to walk long distance. I can access health care when the need arises.

> Istifanus Aidu (Older male affected with Leprosy)



I mostly go to this chemist to buy medicines for my son when he is in pain, the owner of the shop is so familiar with me that sometimes he gives me the medicines I need on credit. This is the closest medicine store to me and it is easy to access with or without money.

Jamila Sallihu

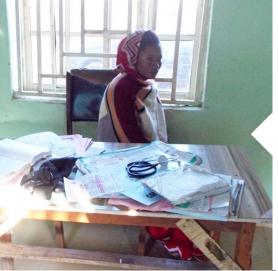
(Caregiver of Musa Alhassan, a person affected by Lymphedema)

This is where I was once admitted on this same bed because I was sick. My whole body was in pain and I could not even stand properly but when I got to this health centre, I was well accepted and treated until when the pain subsided and I was able to go back home. It is the closest clinic in my community. I can get there within seven minutes therefore enables me quick medical access when in need of care.

Zaiya Nuhu

(Older female affected with Leprosy)





It's the photo of our doctor. It relates where I receive medicines, the man always treats me nicely and makes me feel respected I like him so I took his photo.

This is the closest hospital to my house, no matter how I feel even if its a headache this hospital always caters for me.

Alhassan Musa

(Younger male affected with Lymphedema)

This is my family friend, she runs her private clinic in my community which is only five minutes from my house. I always run to seek medical care or advice with regards to my ill health which she gladly offers at all times. Am so glad that I can reach her without traveling long distance to seek medical care.

Rebecca Ayuba, co-researcher

(Older female affected with Leprosy)



This photo shows the very place where I lie down every time of the day. I cannot afford regular care and check up at the hospital where my leg can be checked and the dressing changed as often as possible so whenever I feel sick and my leg begins to give out discharges, it is these pillows I use in draining or soaking away the discharge.

Tanko Mohammed

(Younger male affected with Lymphedema)





This is a photo of a Tamarind (Tsamiya) tree which is in the hospital I was invited to; its seed is processed into food; also the back of the tree is used as herbal medicine. It represents the hope I am anticipating to receive by being left here in the hospital.

(Younger male affected with Hydrocele)

RELATIONSHIPS WITH OTHERS, SUPPORT AND ACCEPTANCE



THEME SUMMARY

Participants spoke of the support they receive from friends and family and were keen to give recognition to their caregivers; frequently expressing gratitude toward them. Many accounts focused on how the support received, whether this be in enhancing their appearance through new clothes or support with daily tasks reflected acceptance by their peers or loved ones and invoked positive feelings. Despite these positive relationships, participants described a dependence on caregivers or members of their household. Some family members provided support by contributing funds from their income, by providing clothing or assisting with daily activities such as fetching water, laundry, farming, and cooking. Balele Yusuf, a man affected by hydrocele expressed how his role as a father and the unconditional love of son also provides support to him.



These are the clothes that I saw were good and decided to get for him so he can wear them and be clean so he can be presentable before people.

Magaji Isiyaku

(Caregiver of older male affected by Leprosy)

This is the food called olailai (grinded bean) my care giver gives to me at the time to take my medicine and that is why I took the picture to show you what kind of support I get. Whenever I see this picture, I feel loved that my care giver is trying all efforts to see that I regain my strength and return to my healthy self. She is supportive and takes good care of me because whatever I think of, she does it like she knows what is in my heart.

Abdullahi Musa 1

(Older male affected by Leprosy)





These are clothes I gathered for washing when they get dirty.... It says to me that I should be clean and hygienic, when my husband was sick, I was the one who provided what to use to wash clothes.

Mariamu David

(Caregiver to David Irimiya, a person affected by Lymphedema)

My wife has always carried out several activities for me such as fetching water for me to bath, washing my clothes, etc. Truly, with regards to my health, this photo shows the help I receive. She 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. Looking at this photo, I wonder who would have been able to take care of me like this if I did not have my supportive wife.

David Irimiya

(Younger male affected by Lymphedema)



It is a sewing machine which the owner has helped me, she asked me to come along with clothes to sew for me because my clothes are all torn and people look at me with scorn because of the torn clothes I put on, I've worn the clothes she sown for me and I am happy. I am not related to her. She just had pity on me and decided to sew clothes for me.

Aliyu Yusuf

(Younger male affected by Buruli Ulcer)

This is the photo of my niece she does my laundry and gets bathing water for me, she is always willing to wash my clothes because she likes to see me clean even with my ailment.

Shuaibu Abdulkadir, co-reseaercher

(Younger male affected by Lymphedema)





My son comes close to me unlike other people who won't, and eats whatever I am eating, he is part of me because I am his father. I feel relaxed and happy that no matter what, my child is happy with me and the idea that he looks up to me keeps me going no matter the setback my ailment has caused me. It makes me feel happy and responsible, it brings smiles to my face just as you can see now.

(Younger male affected by Hydrocele)

This is my husband. Why I took this photo is that he always support me. Since I fell sick, he has never shown any sign of disgust towards me or avoided me but instead he takes care of me.

Ga'aje Saleh (Younger female affected by Leprosy)





This is a photo of my granddaughter carrying building blocks. I do not have the strength and ability to be part of any groups. Well, except my children make effort in providing for me what to eat and the means to meet my needs. I feel blessed and grateful, having a granddaughter that takes so much care of me. If she were not here, I do not know what would have become of me.

Istifanus Aidu

(Older male affected by Leprosy)

This is a photo of my father with ailment and I giving him medication. This happened while I was working in the farm, I was called as my father was not feeling well, I left the farm and dashed to the house got his medication. That day I was unable to go back to the farm again. His condition takes all my time, I need support on how to get him well so I can do other things without getting worried.

Solomon Aidu

(Caregiver to Istifanus Aidu, a person affected by Leprosy)



PSYCHOSOCIAL WELLBEING



THEME SUMMARY

Negative impacts on psychosocial wellbeing as well as activities and coping mechanisms were highlighted by participants. Psychosocial wellbeing was often linked to factors described in other themes identified as well as described through standalone images. For example, Saidu Adu, an older man affected by leprosy described anxiety, worried thoughts, and his belief that mourning his late wife led to his condition. The psychosocial impact on caregivers was also highlighted by Aliyu Yusuf, a young man affected by Buruli ulcer who described his mother's distress and concern on how to treat his condition. The invisibility of psychosocial wellbeing was shown by Aliyu who emphasised how his mind feels locked. Ways of positively impacting psychosocial wellbeing included safe spaces and seeking shade under trees; Istifanus Aidu described how sitting under a tree and being amongst people improves his mood and helps take his mind off his thoughts and worries. Music was described as a tool for feeling less lonely, and spiritual wellbeing was also highlighted as critically important in managing pain.

This photo is about me in my thoughts. I was once married, and my wife died of stomachache. Mourning her death led to this ill health of mine. This photo also portrait my worries and in deep thoughts hoping that someday I will get well.

Saidu Isah

(Older male affected by Leprosy)

This is the photo of my care giver, she was worried because I had nothing to eat...[She] was disturbed with thoughts on the issues of my condition, to the extent that she couldn't even look at me.

I feel like my head is locked up because of my ailment. It shows how much I need help to get better so I can stop feeling this way in my head...I am not fine as a result of this ailment, I always feel as if my head is under a lock and I think a lot but if am fine I will not be feeling like that and my head will feel open and I will understand things...even though I look healthy on the outside, I am really not healthy.

Aliyu Yusuf

(Younger male affected by Buruli Ulcer)





This is a radio, when I'm left alone since I am not fully very healthy, I put on the radio to keep me company and I don't feel lonely.

Shuaibu Abdulkadir

(Younger male affected by Lymphedema)

Whenever I feel downcast or sad, I go here and sit amongst people. Being with people and listening to them speak helps in getting me out of my moody state. This is the reason I took this photo. I only go there when I feel downcast. I feel better because being there takes my mind off so many thoughts and worries. Various thoughts especially of the past because I was not always this idle.

Istifanus Aidu

(Older male affected by Leprosy)



This photo show that when my children go out to the farm and I get hot inside, I go out and follow this path to get some shade under this tree. I enjoy the place and feel good and relieved.

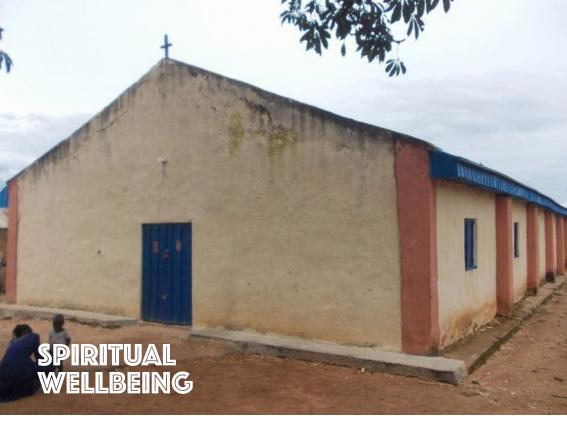
Rebecca Ayuba, co-researcher

(Older female affected by Leprosy)

It's my room I swept it and it looked nice and lovely and I felt good about being able to carry out this function so I took a photo of it.

Ga'aje Saleh (Younger female affected by Leprosy)





When my legs ache and the pains become unbearable, I go to the Church for prayers to be made for me, I hope to get completely well some day. It makes my mind relax and feel peaceful.

David Irimiya

(Younger male affected by Lymphedema)

FOOD AND ENVIRONMENTAL SECURITY



THEME SUMMARY

Food security, environmental interactions, and the built environment were depicted as emerging themes or factors that positively affect the health of participants. Food was widely captured across participants who emphasised the importance of nutrition for promoting good health. Tanko Mohammed, a young man affected by lymphedema used the example of a chicken being healthy due to having enough food to eat and being able to roam freely. Trees represented medicinal environments through providing shade as well as benefits such as herbal medicine. The built environment was often used as a metaphor to describe feelings and hopes for the future for example, Abigail Ayuba a female caregiver expressed her desire for her mother to get better so she can live in nicer surroundings to rest and recover, while incomplete buildings were photographed by Abdullahi Musa, a male participant affected by leprosy to demonstrate how his illnesses have hindered him from completing his house.



This photo shows thrashers who do the milling of the corn. To me, this photo expresses that if there is sufficient food all will be well with me, and others around me. Also, if there is good food it would improve our health and living. Looking at this photo, I feel very happy.

Adamu Saleh

(Young male caregiver of Da'aje Shaleh, a person affected by Leprosy)





The photo contains soup ingredients. It is for good health I feel happy when I look at the photo because of what it contains and how it help to nourish my body.

Bello Abdullahi

(Older male caregiver of Shuaibu Abdulkadir, a person affected by Lymphedema)

This is a cashew tree. When mama's body becomes hot, she usually sits under this tree and has some fresh air to feel good in her body.

> **Abigail Ayuba** (Caregiver to Rebecca Ayuba, a person affected by Leprosy)

This is a photo of a plant called Ramah. It is a plant we eat because of its nutritional value, when sometimes we don't have enough food in the house we boil and eat the leaves of this plant for its nutrition and medicinal value.

Rebecca Ayuba, co-researcher

(Older female affected with Leprosy)





What this photo is saying is that, the cock is eating and as a result of its healthy state that makes the cock to able to feed, and roam about without any restrain... It is my desire for every human to live a better life, I don't like to see anybody living in pain due to health complications, I want everybody to live freely just as the cock in the photo.

Tanko Mohammed

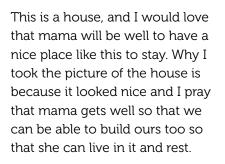
(Younger male affected by Lymphedema)

BUILT ENVIRONMENT

This illness has deprived me from completing this house.

Abdullahi Musa

(Older male affected by Hydrocele)



Abigail Ayuba

(Caregiver to Rebecca Ayuba, a person affected by Leprosy)



RESEARCH TEAM AND REFLECTIONS



I am Shuaibu Abdulkadir 45 years of age, married with 5 children. I am a co-researcher in this study. I live at Kurosha and primarily a shepherd and farmer before I came down with this ailment that affected both of my legs. It is really a thing of joy to be part of something that would help other people who may be suffering with skin stigmatizing diseases like me.







I am Rebecca Ayuba, a mother of 6 and a grandmother of many. I live in Nasarawa Ladi Maigamo with my children and I usually farm maize sometimes when am feeling stronger. I am a co-researcher in this study. I am happy to be part of this program that is trying to help people like me who have been suffering and no one in the past has been paying attention to us.



'Being part of the wellbeing team is a learning experience, helping affected persons and caregivers so the world could hear their voices, on what they feel or are battling with through the use of photovoice is a wonderful and fulfilling experience.'

Edward Stephen Ozokede, Field Assistant, Sightsavers, Nigeria

'One thing I learnt is meeting and relating with people.' Istifanus Aidu, older male affected by Leprosy, photovoice participant



'Taking these photos was a challenging experience, first learning how to handle a camera, focusing it and taking a photo, more so knowing what to take and explaining it in relation to what am going through or facing was a new experience to me.'

Isah Saidu, older male affected by Leprosy, photovoice participant

Photovoice was an interesting process for me, meeting all the participants working together and achieving a common goal of making their voices heard through a unique process of photovoice.

Mcrea Ayuba, Field Co-ordinator, Sightsavers, Nigeria



'It's been an exciting experience participating in photovoice and having to interact with all the participants I have learnt a lot listening to them and understanding how they have lived their lives in spite and despite their health challenge. I have now gained a new skill with photovoice.'

Linda Dubukumah, Field Assistant, Sightsavers, Nigeria

'I learnt how to take pictures and then being able to explain what is in the picture and now I can even teach someone else.'

Ga'aje Saleh, female affected by Leprosy, photovoice participant



'What I have learnt in this process is living in peace with other people and how I have met with my friends. Before now, I faced a lot of stigmatization even from people who did not know me but seeing me with a camera made the same people treat me differently. People have begun treating me in a positive light because they believe I have gotten a job.'

Abdullahi Musa, older male affected by Hydrocele, photovoice participant

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COUNTDOWN Calling time on Neglected Tropical Diseases

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