



REDRESS

Reducing the burden of
Severe Stigmatising Skin Diseases

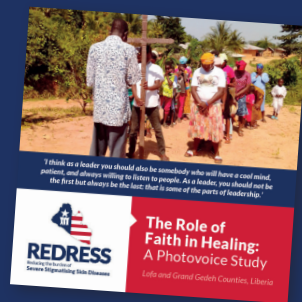
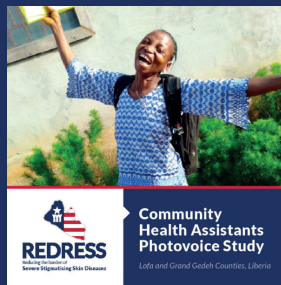
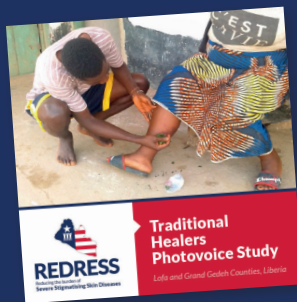
Community Health Volunteers Photovoice Study

Lofa and Grand Gedeh Counties, Liberia

Community Health Assistants Photovoice Study

Neglected Tropical Diseases (NTDs) affect around one billion people globally, often the most poor and marginalised groups in society.

For many persons with severe stigmatising skin diseases (SSSDs) such as leprosy, buruli ulcer, yaws, onchocerciasis, hydrocele and lymphedema, lack of access to effective services results in significant physical, financial and psycho-social impacts. Delayed diagnosis and disease progression cause greater and largely irreversible physical impairment; and alternative treatment is sought from outside the health system, often with economic and social consequences for patients and their households. In-depth understanding of the role and treatments provided by community level providers, both formal (community health assistants [CHAs], community health volunteers [CHVs]) and informal (faith healers, traditional healers) are often lacking. In this project, we seek to understand the experiences of CHAs, CHVs, faith healers and traditional healers in providing care for persons affected by SSSDs through photovoice.



This booklet is one of a series of four, with one booklet created for each group of participants, incorporating findings across two counties (Lofa and Grand Gedeh) and presents the findings of the photovoice activity to identify core issues and themes. These photos will be presented in stakeholder meetings to inform the co-design and implementation of interventions to strengthen the provision of services for people affected by SSSDs at community level. We aim to show the unique role played by these community level providers in supporting people affected by SSSDs and identifying opportunities for earlier identification and initiation of treatment, along with options for the provision of more holistic care of people affected. From this point onwards we will refer to NTDs/SSSDs as skin diseases.



MINISTRY OF HEALTH
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Queen Margaret University
EDINBURGH

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effect:hope
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This project is led by REDRESS, a collaboration between the Liberia Ministry of Health, the Liverpool School of Tropical Medicine (LSTM), the University of Liberia-Pacific Institute for Research and Evaluation (UL-PIRE), Actions Transforming Lives (ACTS), Effect Hope, American Leprosy Mission- AIM Initiative, Queen Margaret University, and is funded by the National Institute for Health Research (NIHR).



Photovoice Methods *and* Consent

Photovoice is a creative participatory method, which aims to empower participants to take ownership and be the storytellers of their own narratives.

Over the course of three weeks, these four groups of participants took photographs within their communities to capture their lived experiences in relation to their work, their interactions with their community and the health system, with a particular focus on skin diseases.

The process involved training of photovoice participants on the use of cameras and ethics of photography. Co-researchers were recruited as part of the core research team, which included people affected by and/or providing care for people affected by skin diseases who then supported and trained other people affected within their communities as photovoice participants to take photographs and articulate their meanings. The study took place in Lofa and Grand Gedeh Counties, within Liberia. These counties were selected to provide comparison between counties where integrated case management of NTDs has been introduced (Lofa County) and not yet introduced (Grand Gedeh County).



"According to REDRESS they trained us that before you can take somebody consent, you should ask the person first and he or she should understand and agreed to fill in that form...And I ask the lady, she has the skin diseases...so before ever I took her photo, I informed her before filling the consent and REDRESS form."

Joseph N. Bundor, CHV, Lofa County

Glossary

Big Bag	<i>Liberian jargon to refer to Hydrocele</i>
Big Belleh	<i>Liberian jargon to refer to a pregnant woman</i>
Big Foot	<i>Liberian jargon to refer to Lymphedema</i>
Black Baggers	<i>Informal service providers who sell medication and treat sick people within the communities</i>
Community Health Assistants (CHAs)	<i>Health workers not employed by the formal health system. They work outside of a 5km radius to health facilities and are trained frequently to treat common illnesses at community level</i>
Community Health Services Supervisor (CHSS)	<i>Has undertaken a 3-month period of training and supervises CHAs/CHVs at community level</i>
Community Health Volunteers (CHVs)	<i>Work within communities that are located within a 5km radius to health facilities to support the delivery of health services on an adhoc basis</i>
Everlasting Sore	<i>Liberian jargon to refer to Buruli Ulcer</i>
general Community Health Volunteers (gCHVs)	<i>Some CHAs were formerly referred to as gCHVs</i>
Grand Gedeh County	<i>One of Liberia's 15 counties located in the South-East and the second largest county. One of 10 counties that is not implementing MoH integrated case management plan</i>

Lofa County	<i>One of Liberia's 15 counties located in the North and the fourth largest county. One of the five counties implementing case management plans</i>
Mid Upper Arm Circumference (MUAC)	<i>Measurement to detect acute malnutrition</i>
Neglected Tropical Diseases (NTDs)	<i>Disabling or debilitating diseases that usually affect poorer populations in tropical and sub-tropical countries</i>
Open Mole	<i>Refers to migraine headache and is often used to describe mental distress</i>
Papay	<i>An older male</i>
Severe Stigmatising Skin Diseases (SSSDs)	<i>Diseases that affect the skin and are associated with negative attitudes or discrimination</i>
Tablet People	<i>Also referred to as black baggers</i>
University of Liberia-Pacific Institute for Research and Evaluation Africa Center (UL-PIRE)	<i>A research center and one of REDRESS' collaborating partners</i>
Zoe	<i>Traditional spiritual personnel believed to possess supernatural powers to curse people and heal diseases</i>



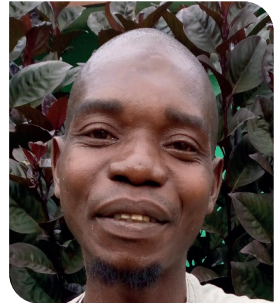


Behind *the* Lens



"My name is **Seoh Dehday**, I hail from Jarson, Cavalla District, Grand Gedeh County. I am a CHV who has been with the County Health Team for the past 3 years and my role as CHV is to go in my community and find cases such as the big bag and refer them and also go from home to home. Yes, I go in the community and go from home to home and if someone is sick, I talk to them to [go to] the nearest clinic."

"My name is **Anthony D. Salay** from Balahun, Old Town community, Faith Clinic, Kolahun District, Lofa County. I have been working with Faith Clinic since 2012. I work as volunteer worker, they sent in the community... I have been working with those people, this year making me 10 good years with the facility Faith Clinic. ...I was the only one the chance came to me; so, I was over happy to work with the people."



"I am **Mary S. Borbor** one of the CHVs [in] Mbalotahun Town, Kolahun District; Lofa County. I started this work 2019 up to now. Some of the work I do as a CHV, I make sure every morning I visit people in the community to know about their problem. So, I am very happy to be with this people or to do this job because it made me to [know] about things or changes in the community... I can visit them [patients] to go [to] the clinic. So, these are some of the work I [do] to refer the patient."



*"My name is **Junior Cole**, I am from Yarleville, Tchen District, Grand Gedeh County. I am a CHV. I have been working with the health team here for the past two years... We are encouraging the parents to take their children for vaccination in the community and pregnant women some of the pregnant women them can't go to hospital; so, we encourage them to [get] hospital card so that they can do their check-up anytime. When the child under five and they [are] sick we refer them to the hospital."*

*"I am **Joseph N. Bundor**, from Ndama road, facility, Foyah Health Center, Foyah District, Lower Lofa. The work I do in my community, in my catchment community is to visit house to house to know the problems in the community. And I have been as CHV 2019 up to present.*

What motivated me to [do] the work, to help our people in the community, to see how best our people cannot come down with these kind of diseases in the community; to give health talk to them. And I feel happy, I feel relaxed. I see myself that yes, we all are the same... I take myself to be like them. I consider myself and the people in the community to be the same; we joke together, we eat together and all."





*“By the way of introduction, I am **Catherine Nahn**. I am from Geoleken Town, Cavalla District, Grand Gedeh County. I started as GCHV 2 years ago. I have [been] working with men, boys and children. And some people when they are sick, they can go to the hospital, they can buy the paracetamol in the bucket (from black bagger). If I see it like that, I can try to put [a] stop to it and I tell [the patient] you go to the nearest clinic let them do your check-up and prescribe your drugs for you and you will be cured.”*

*“My name is **Princess Yillia**, I am the CHV for Shelo, Lofa County. I started working with the people in the community from 2013. I used to help to clean in our clinic. To help to clean grass in the yard, scratching and doing other things. I go into community to talk to my people and tell them about the health to come to the hospital or clinic, the big belleh (pregnant women). The family planning, the vaccine for children, talking to them and encourage them... The thing that motivated me, I want to be helping my people to encourage them; if anybody get sick [I] talk to the particular person to go for medicine to facility.”*





CHV Roles *and* Responsibilities

CHVs carry out a series of key roles relating to SSSDs within their communities, which are often closely linked to the trust and strong relationships they have within their community and with local leaders.

Key roles carried out, relating to persons affected by skin diseases include negotiations with community leaders, providing health education to raise awareness about diseases and carrying out home visits to identify and refer priority diseases, as part of active case finding.

CHVs also highlighted some challenges with accessing communities, with CHVs needing to cross monkey bridge to reach remote communities. One CHV with limited mobility needed to use a motorbike in order to reach some communities.



"As you can see the CHV sits with the old man, talking to him and giving him community health talk, telling him about the priority diseases and what is the effect. So, these are the roles I was playing in the community; house to house visitation. That's my job aid in my hands and you can see my bag with all of my tools inside to know when you go on the battle front to fight against the priority diseases in the community and not for us to get the diseases in the community...I say "oh these are the work we are doing to talk to you, if you get sick, we give you the referral form and you go for your treatment to the facility and you come back,...When they give you the feedback then you bring it to us we the CHV, we will be monitoring you."

Joseph N. Bundor, CHV, Lofa County

"As you can see, this is the Town chief. I can do the community [work] and I am not doing it on my own; the concern of job is the community. The town chief agreed first before I can do the work... Even the photo taking, they were aware of that; they said is good, thank you for your respect they gave me the go ahead to take the photo."

Mary S. Borbor, CHV, Lofa County



"You see the photo, this person is suffering from BU, Buruli Ulcer (skin disease), it is on that foot, among the five trigger [surveillance diseases] we have been finding."

Anthony D. Salay, CHV, Lofa County



"You can see me sitting down wearing my vest (CHV uniform), I [am] on the bike to go [to] other communities to go and do health talk. That's how I talked to my man I say 'please carry me there' because this time that the farm work before you get to the people, you have to schedule them in the morning before you meet them in the town to talk to them. But, if you don't go there quickly before 8 to 9 O'clock, you will not meet them there to talk to them. So, I got on this bike to reach quickly and give them health talk."

Joseph N. Bundor, CHV, Lofa County

"As you can see this other photo, I am wearing my jacket, I was about to go and do my visitation to the community so, the youths can see me in the jacket for me to be identified."

Mary S. Borbor, CHV, Lofa County



*"This is a monkey bridge...
I can cross to go to the
nearby villages to do
health talks about the
priority diseases that are
in the community. As a
CHV we go all around
to do the health talk,
to go to place to people
and talk to our people
for good health because
health comes first in our
lives."*

**Joseph N. Bundor, CHV,
Lofa County**





"So, as you see the papay (older man), the papay was about to go to do his job but luckily I met him and gave him health talk. While I was giving the health talk to the papay about the priority that we are discussing, this is why the papay was trying to tell me that "as you can see my sore, he lift up his trouser, "you see my foot how is looking? The suffering I am undergoing, her me here [here I am] now, except I cut contract and I get my soap money self or sometimes I can go to the clinic. If I go to the clinic they give me paper [prescription] they say go and buy medicine and here I am now, if I don't cut contract, I will not be able to buy medicine they can say go buy it"."

Mary S. Borbor, CHV, Lofa County



Compassionate Care

CHV participants highlighted the range of ways in which skin diseases impact persons affected, including physical pain and discomfort; physical disability; which can create limitations to pursuing education and employment; social stigma and isolation from family and the wider community. The strength and ability to find solutions to these challenges by persons affected was also clearly described by participants. The longevity of experiences for persons affected by skin diseases, and the CHVs' feelings of empathy and desire to provide compassionate care were further highlighted. Examples shared by participants include the need for a person affected to find alternative employment selling shoes, carrying out farming activities and the determination of a student to continue pursuing studies, despite pain due to a persistent ulcer.



"Yes, as we can see this guy, he's a shoe repairer... because he has sore on his foot. He has six living children and he said that he can go on the road and do this thing (repairing shoes). He said he can't go in the village and do farming since this thing occurred one year ago. He came for medical attention and brought his children here and his wife left him here, he and his children are struggling and he can go on the road to repair people shoes before his children can survive and go to school."

"This is a photo of a woman who has been suffering from this big leg (skin disease).

According to her she said that she been struggling for the past one and a half years and she's not married according to her. Her children [depend] on her for everything and now she's not able to move from one place to another to get her daily bread. And since no medical attention has been drawn upon her, so she's suffering."

Junior Cole, CHV, Grand Gedeh County





“Ok, you see this brother’s foot, he been suffering for two years ...I asked him how best he’s been taking the treatment and he said anytime he goes to the hospital for treatment they will tell him say ‘no drugs, yes no tablet at the hospital or the facility’. I say but how? He said ‘oh I have been taking treatment from drug store’... I asked him but he said he doesn’t have money to go to other places.”

Joseph N. Bundor, CHV, Lofa County



“This photo as you can see is big foot (skin disease) and the person has sore on the leg, the person can’t walk, they just remain to the same position... although we are doing voluntary work but let us come to her rescue, because she’s not living a good healthy life.”

**Seoh K. Dehdey, CHV,
Grand Gedeh County**

“The meaning of this photo is to have the patient to talk to the people, this particular person that has this problem to talk to him to take medicine anytime. The photo I have is the sore, the big sore in the photo. This woman been sitting down for three months.”

Princess Yillia, CHV, Lofa County





"As you can see this foot condition, this guy is still going to school... This guy is not in healthy condition but everybody saying that education is the key. So, everybody wants to achieve their goals. When this guy is going on campus, you will see him, he will bandage this foot and do any other thing. When weekend reaches then he goes back to the village for food. And this guy when I explained to him, he said 5 years...So, I myself I was feeling for him and I was feeling sorry self to take the photo."

Junior Cole, CHV, Grand Gedeh County



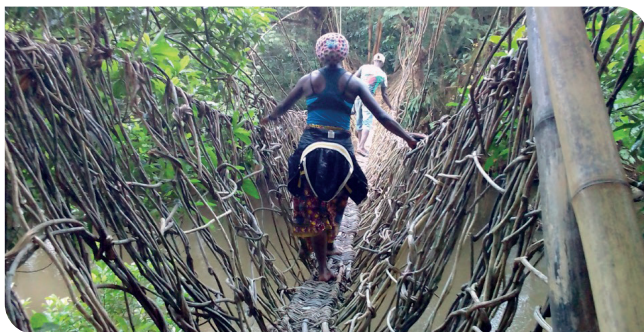
"When we carry those photos [of skin diseases] that's how he explained, he say 'myself that's the same condition that on me, but for me I am afraid to go among people because they say leprosy (skin disease) it can travel so, I can't go around anybody, the way you come around me here, I am worried'. So, I said 'by the help of God, it can't catch me, for me I am [a] friend and we are friendly, we just want to know the condition'. He said 'you try and tell your people to help us'."

Catherine Nahn, CHV, Grand Gedeh County



Access to Care

Persons affected by skin disease experience challenges with accessing effective care and may seek care from informal health providers. The CHVs described the role which they play in identifying and referring persons affected to a health facility. Affected persons experience challenges in reaching facilities such as difficult terrain, remote location and the need to cross unstable bridges. Local solutions to reaching the health facility were also described, such as use of motorbikes.



"As you can see this [is a] monkey bridge, people walk on it to come to the health clinic or to come to the hospital. And besides, the big belleh (pregnant women) they will be sick and they will take the big belleh ... within the monkey bridge. These are some of the challenges our people undergo across there."

Mary S. Borbor, CHV, Lofa County

"For this lady with her big foot (skin disease)...she said 'my people I am looking and I have gone all over. You see the country chalk on my foot'. So, I said 'no country [medicine] cannot solve your problem, go to the hospital, we can't assure you to say you will bring medicine today or tomorrow'...She was showing me her foot and she's recommending that the people should be able to help if they see her condition."

Catherine Nahn, CHV, Grand Gedeh County

Community Trigger & Referral Form

Section A Referral (Community → Facility) The CHA/CHV fills this out and submit to the Health facility (CHS, CHC, etc.) to be triaged immediately.

Patient Name: _____ Community: Adana Road

Sex: ☐ Male ☒ Female Facility or POE: FHC

Date (DD/MM/YYYY): 11/11/2020 CHA/CHV Name: _____

Patient Age: 110 Years ☐ Months CHA/CHV Phone Number: _____

Crossed Int. Border in last 1 month ☐ Yes ☒ No IDSR-ID: _____

Partly Notifiable Triggers

1 Acute Flaccid Paralysis (Poli)	10 Neonatal Death (Young baby death)
2 Severe Acute Watery Diarrhea / Cholera (Runny stomach)	11 Dengue fever (Hot skin and strong pain behind the eyes)
3 Acute Bloody Diarrhea (pu-pu with blood)	12 Monkeypox (Hot skin burn on the face, palm of hand and feet)
4 Human Rabies (Dog/bany other animal bite)	13 TB (Coughing plenty, sweating and getting dry)
5 Measles	14 Yaws (Swollen that burst into sores)
6 Viral Hemorrhagic Fever (Ebola, Lassa fever, Yellow fever)	15 Burnt Ulcer (Sore or swollen on the body that is not healing)
7 Meningitis (Stiff neck)	16 Unknown health problems grouped together
8 Maternal Death (Big belly death)	17 Any death in human or group of animals that you don't know why it happened
9 Neonatal Tetanus (Sneaking sickness)	<input type="radio"/> Other (write in): _____

☐ Family Planning ☐ Child Health ☐ Maternal & Infant Health

☐ Child Vaccination ☐ Tuberculosis ☐ Leprosy

☐ Mental health ☐ HIV ☐ Other

Describe any investigation or treatment

Section B Counter-Referral (Facility → Community) For the Health Worker: The patient should be sent to the CHS to take to the CHA/CHV

Patient Name: _____ CHA/CHV Name: _____

Facility Worker Name: _____ Community: _____

Case Definition: _____ Health Facility: _____

Facility Worker Position: _____

Address (tick all that apply)

☐ Treated and sent home

"As you can see this photo, in this photo we have the road to go in the village but on this road we will ask motorbike to carry us but they can't come here because the road is not too correct."

Princess Yillia, CHV, Lofa County



"You can see this photo is really telling us that these are roles for CHVs to play and then these are community triggers and then these are referral forms in my hands. I can refer the patients to go to for treatment to the facility. This patient was sick that's why I gave her the referral form I say go to the hospital and get your treatment... This paper we gave you, the main thing... about this referral form is when you get to the facility you will not go stand up in line. By the time you get there, they will consider you straight and say that community health workers sent the patient."

Joseph N. Bindor, CHV, Lofa County



“As you see this structure, this is a hospital building, a very nice structure, you can see it. This is what we want to be in the community because health comes first. When we get good hospital or good facility or where the citizens can get good treatment. So, this is a hospital.”

Joseph N. Bundor, CHV, Lofa County

“Ok, this is a photo as you can see a bike and this man. This man is trying to service this particular bike; it is good for the transportation system. In case anyone is ill or sick at that particular moment, that bike will be used to transport that particular person. So, it has a part to play in the health system.”

Seoh K. Dehday, CHV, Lofa County





Environmental Awareness

CHVs emphasised the connection between the local environment and some skin diseases, with standing water, dirty water, or rubbish dump sites being seen as potential sources of vectors which may contribute to the spread of some skin diseases. For example, one participant highlighted that standing water may lead to more mosquitoes, which can contribute to the spread of lymphatic filariasis leading to more patients developing skin disease (lymphedema/big foot).



"The hole we see inside there, it is in the grass and also dirty water there within it. They chunk [throw] lots of things in that hole. Mosquitoes also in that hole and we say it is a death trap also. When you are a big person, you see it and you go inside it can harm you and when mosquito comes from there when it bite you, you either get big foot."

**Catherine Nahn, CHV,
Grand Gedeh County**

"As I was saying, I said you can't see this kind of dirty water then you get this sore to go and play inside this kind of area or you get this sore and then you sit in this area to start to eat, it will not be good for us. So, it is relating to skin diseases."

**Catherine Nahn, CHV,
Grand Gedeh County**





“Yes, as you see this is a dumpsite that is bad for our health. This particular dumpsite is around Zwedru market. Everybody from the market dump the dirt and at the same time sitting down around the dumpsite, eating their food and cooking their food, it is bad for our health.”

Catherine Nahn, CHV, Grand Gedeh County



Opportunities *for* Action

CHV participants identified a number of potential opportunities for action, including using their vote wisely when electing local politicians and holding local politicians accountable to deliver on election campaign promises. Participants also highlighted a range of options for local awareness raising through existing community structures and organisations, such as local dance groups, which could be leveraged to raise awareness about skin diseases.

"This photo here, he's showing love to his candidate, he can do anything for the man. At the end of the day he write (wrote) the man name on his chest. You see him, he fixed himself like statue."



"This is called santa claus (traditional mask dancer), others don't know but everybody has a tradition and they believe in their traditions like us. So, this santa claus (traditional mask dancer) you see here, it walked from long distance, almost 3 hours just to come to Zwedru or to come to where they are going to see who they want to see."

Junior Cole, CHV, Grand Gedeh County

"Alright, this photo as you can see people in the queue, and they are going to make decision for their Senator. So, the people are going to the election hall to go and make decision for themselves."

Catherine Nahn, CHV, Grand Gedeh County



"Yes, when you make good decision here, those people with SSSDs will get a good health facility and get a good healthcare from the lawmaker that we are going to elect; but if you elect someone who is not in the interest of the citizens, you will see that those that have those kind of sickness like SSSDs, they will not be listening to them and they will not get time [to] talk to them. So, is good that we elect our own leader that we trust who will talk for our people that are having these kinds of sickness."

Grand Gedeh CHV Group Discussion



"You can see this group, these guys they are dancing group, they form part of the cultural dancing, they want to show where they come from, they generate funding for the other guy and they mobilised other group to go and vote. So, this guy is a cultural dancer as you can see. So, you can see this guy is a cultural dancer."

**Junior Cole, CHV,
Grand Gedeh County**



Recommendations of actions for change *from CHVs*

CHVs recommended a series of actions to better support people affected by skin diseases. They emphasised the need to understand people affected, ‘to be in their shoes’, make friends and to counsel and refer them to the health facility for treatment.

CHVs also emphasised the importance of needed tools to enable them to carry out their work, including rain gear, bag, personal protective equipment, job aides with photos to guide the identification of patients during household visits, and payment for their work.

“So, identifying a person with such condition you have to visit them, go to them, make friends with and encourage them; and then... speak to the level of the people. And also for the everlasting sore (skin disease), we already know that there are sores that can be found on our legs and also on our hands. So we are set for those conditions, firstly we have to know where those conditions can be found. For example, the big foot (skin disease-lymphedema), the big foot can be found on the legs, so we make friends with them and you have to visit them.”

Grand Gedeh CHV Group Discussion

“I said we the CHV also can talk to the patient before you can refer the person, you should take yourself in the same shoe...because they also are human being and you who are talking to them, you are human being. ...So, you need to go closer to them, to talk to them and encourage them to see how best they can come to themselves. It is true that this man give me this advice, it will encourage them.”

“Ok, you see this photo ... I identified him with this problem through this job aid. I identified him, he did not believe it until I showed him [the] photo first. He said he didn't believe it; because he saw the photo and he felt in himself that 'yes I have the same problem'. That's how [I] identified myself to him. You understand it; because this household visitation we can go we can teach them all the problem.”

Lofa CHV Group Discussion



Reflections on the Photovoice Process *from CHVs*

CHVs shared how participating in the photovoice study helped them to reflect on the positive and negative things within their communities. CHVs commented on how they now have greater awareness about the lives of people affected by skin diseases and the photography skills gained through participating as co-researchers.



“This research made me to know the changes; what is wrong thing and good thing. It made me to know all this, the bad and the good, yes. And you can see the photos are placed in different groupings. So, REDRESS made me to know all this, I have gained knowledge from REDRESS Liberia and I am happy to work with REDRESS anytime.”

Lofa CHV Group Discussion

“They [people affected by skin disease] are not living a good life, they are not healthy in body, ... people mocked at them, other are going to school without good care, but still we talk to them and we took their photos... So, I feel so happy about the REDRESS family. It gives us experience again pertaining to the CHVs. There are some of us we have experience again because from the starting part, we were not [able] to use phone to take photo; but now we are using phone. So, we have experience again that we can go on the field and talk to other people and they understand us.”

Grand Gedeh CHV Group Discussion

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For further information please see:



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