

COUNTDOWN

Calling time on Neglected Tropical Diseases

ESTABLISHING COMMUNITY-LED SUPPORT GROUPS FOR PEOPLE AFFECTED BY SKIN NTDs



A FACILITATOR'S GUIDE DEVELOPED IN PARTNERSHIP WITH
PEOPLE AFFECTED IN KADUNA AND KWARA STATES, NIGERIA



Sightsavers



SUPPORT GROUP MANUAL

BACKGROUND

Neglected tropical diseases (NTDs) have been documented to cause distress in affected people and their caregivers, because of both their direct impact, stigma and discrimination. Distress which can be *psychological*, comprises the worry, fears, sadness and insecurity often experienced by people with an NTD and the associated stigma. It can result in reduced social functioning, self-isolation and the development of mental health conditions such as depression and anxiety. Photovoice was used as a method to capture the lived experiences of people affected by NTDs through photos; this presented a reflection of life through their lens. These photos were then presented in stakeholder meetings to inform the co-design and implementation of support groups, in partnership with affected persons, caregivers and programme implementers. This guide to establishing support groups in Kaduna and Kwara State Nigeria is the product of collaborative discussions between people affected by skin NTDs, NTD programme and TB/Leprosy programme implementers. The guide could serve as useful to other actors wishing to establish support groups for people affected by NTDs in other settings.

STEP ONE: IDENTIFYING SUPPORT GROUP MEMBERS

Locating people affected by NTDs to come together within a support group can be challenging, as many are often dispersed across communities. To overcome this barrier in our work, we set up a tiered support group structure. This meant that we had different levels of support group cell as described below.

Other techniques can be used to identify affected persons and to understand if they would like to be part of support group activities, including:

- ✓ **Encouraging people affected to share the idea of the support group with each other through word of mouth.**
- ✓ **Working with local health facility and NTD programme staff to identify affected persons who may wish to engage.**
- ✓ **Distribution of support group leaflets or on IEC materials for community sensitisation and awareness so that the people at the community level can be educated and properly informed about the diseases and the support groups process.**
- ✓ **Engage community leadership structures (e.g. local chairman, religious leaders etc) in order to inform them about the support group so that they can encourage other persons affected to join the group and also to gain support for the groups.**

STEP TWO: ESTABLISHING THE SUPPORT GROUP PURPOSE

An initial step in establishing the support group is to agree a common purpose amongst people affected who will be engaged. We did this by asking group members what they envisioned as being the aims of the group and jotting them down on flip chart. These points were then prioritised using a voting system to establish the main purpose of the group.

THE PURPOSE AGREED WITHIN OUR SUPPORT GROUPS WAS:

To bring together people affected by skin NTDs and their caregivers in a safe space to:

- Share common concerns, experiences and challenges.
- Foster open and honest communication.
- Facilitate physical and emotional support.

STEP THREE: AGREEING MEMBERSHIP GUIDELINES AND PRIORITY AREAS OF FOCUS

Once the purpose of the support group is established, agreeing membership guidelines and priority areas of focus for the group is also essential. We did this by structuring conversations with people affected by skin NTD on the criteria of membership, discussing who would be included within the group and deciding what areas they wanted their group to focus on; NTD implementers contributed based on their experience of what would be feasible. Group members were asked to list their priorities, and these were put to a vote. The most popular priorities were therefore chosen as areas of focus.

THE MEMBERSHIP CRITERIA AGREED WITHIN OUR SUPPORT GROUP WAS:

- The membership of the group would be an open one to anyone affected by NTDs and their caregivers. Details of members should be documented in the membership register (an example register can be found in the annex).

THE PRIORITY AREAS WERE:

- ✓ Provide a space and supportive network where people living with skin NTDs can share experiences and challenges confidentially
- ✓ Provide mutual psychosocial support, with shared discussions on how best to deal with challenges.
- ✓ Discuss how to manage conditions and live positively.
- ✓ Strengthen knowledge about conditions and share health information.
**Those affected that are not in treatment will be educated about treatment and management options and directed to health facilities.*
- ✓ Initiate group savings processes through **monthly membership fee of N 100 at district level** used to run the group and help meet smaller needs of the members.
- ✓ Facilitate opening a bank account where money collected can be kept.

STEP FOUR: AGREEING A CODE OF ETHICS

Making sure that participants feel safe to participate in support group activities is essential to their success. We did this by asking group members what they believe would be important to include in a code of ethics. We also highlighted different aspects of code of ethics with examples from other support groups in literature; we picked one code at a time and allowed participants discuss and agree how it would apply to their group. Consensus was then drawn from members, checking that everyone understood and agreed with the points.

OUR CODE OF ETHICS IS OUTLINED BELOW:

- **Confidentiality** - Each member must be certain that any information they share with the group will not be discussed outside group boundaries without his or her consent.
- **Empathic listening** - listen when others are speaking.
- **Respect others opinion** - there are no right or wrong answers.
- **Respect for time** - members should come on time and keep to time.
- **Support the participation of all members** - this is encouraged from every group member.
- **Phones should be on silent during meetings.**

STEP FIVE: ESTABLISHING A SUPPORT GROUP STRUCTURE

Members should agree together when and how they would like to meet and the roles and responsibilities of different support group cells. Based on the geographic area where the support group is being established and the number of affected persons to be engaged, you may wish to consider a tiered support group structure.

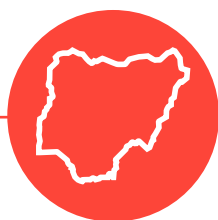
Our support group structure was tiered to allow for more frequent meetings and engagement of people affected who live in less geographically accessible areas.

TWO SUPPORT GROUPS WERE ESTABLISHED: ONE COMMUNITY BASED AND ANOTHER DISTRICT (LGA) BASED.

- The community groups will meet weekly for one hour from 10am - 11am (1 hour)
- The district group will meet monthly for two hours on the last Thursday of every month from 10am - 12pm (2 hours)
- Leaders of the group at the different levels will be selected by the members of the group themselves.

To agree the roles and responsibilities of key group members within the different support cell structures, you should agree on what roles would be important within the group. We did this through reading out different roles while group members discussed what roles would be applicable to their support group and why. Following this, group members nominated and selected who they believed would best suit the position, and explained their reasons for their selection.

Our peer support cells agreed the following key roles and responsibilities at the different levels and all members were elected during the support group planning process.



DISTRICT

The chairman will be responsible to coordinate meetings at the district levels, and work in coordination with the LGA team to arrange external inputs as needed.

The secretary will take attendance and minutes of each meeting, report absences to the group leader/facilitator or to fellow members.

The treasurer will keep financial records of membership fees and other funds of the group and give regular financial reports to the group when requested.

The State and LGA Teams will have a supportive role to ensure meetings run as planned and liaise with external facilitators.



COMMUNITY

One leader/facilitator will be selected per community who will coordinate the affairs of the weekly meetings, pass necessary information to their members at the community level, and encourage their members to attend district meeting regularly.



Support group leaders have **supportive** roles and act as coordinators rather than authoritative roles.

STEP SIX: AGREEING A MEETING VENUE

Making sure that the venue selection takes into consideration the following factors is really important:

- ✓ **Accessibility**
- ✓ **Cost and distance**
- ✓ **COVID-19 guidelines on social distancing and numbers of people at group gatherings**
- ✓ **Central Location**

The venue and or location of meetings should be agreed by all participants.

STEP SEVEN: ESTABLISHING PRIORITY TOPICS AND MEETING DATES

Vocational training and skills building activities are often key priorities of affected persons and many think that engaging with these activities contributes to the success of the support group. Within our study, we used the photovoice activity that we completed with affected persons to establish priority areas or meeting topics to be covered within support group activities. You do not have to go through a whole photovoice activity to complete this prioritisation, but should making having a participatory dialogue with support group members to establish such focus a key priority within the first support group meeting. You could do this using flip charts and pens, or just facilitating a discussion on what skills affected persons would like to develop.

The table below shows the priority areas that support group members in our peer support cells chose to focus on over a six-week period.

MEETING TOPIC	FACILITATOR
Establishing meeting structure including community meeting and roles	Selected Group Leaders
General health Care and Disease Management and financial issues (registration fees & support for members)	Invited Community Health workers
Wound Care & financial issues (registration fees & support for members)	Invited Community Health workers
Vocational Training/Skills Acquisition, financial issues (registration fees & support for members)	State NTD team
Social Skills, building self-esteem re-engaging with the society, coming out of isolation financial issues (registration fees & support for members)	State NTD team

You will see from the table above that engaging with other actors to provide skills building activities is also essential to their success. These engagements should be led by support group leaders with active support from NTD programme staff.

As well as establishing key meeting topics, our peer support group members preferred to have a standard agenda so that each district meeting had a formal structure. An example of the agenda can be found at the end of the guide. This is something you might wish to consider discussing with peer support group members.

OTHER TOP TIPS

Ensuring that peer support cells are adequately supported by the NTD programme is essential in taking forward key activities and ensuring the safety of all participants.

SUGGESTED EXTERNAL SUPPORT STRUCTURES INCLUDE:

- ✔ **Health workers to give advice on wound care, drug use, physiotherapy and general medical advice.**
- ✔ **Social workers could give psycho-social support to group members.**
- ✔ **State NTD Staff to create awareness about skin NTDs for community members to clear any misconceptions.**
- ✔ **State TB and Leprosy programme to support with links for referrals (in cases of complications in leprosy cases) to other specialist hospitals and supply foot wears for persons affected with leprosy.**
- ✔ **Sub national and district level implementers to provide staff who will conduct training on skills acquisition.**

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ANNEX

AGENDA FOR DISTRICT MEETINGS

GENERAL STRUCTURE AGENDA FOR DISTRICT MEETINGS

AGENDA	TIME
Opening prayer and introductions	5 minutes
Light exercise and singing	5 minutes
Minutes of the last LGA meeting	10 minutes
Issues raised at the weekly meetings	15 minutes
Main topic	60 minutes
Discussions and any other business	20 minutes
Closing prayer	5 minutes

MEETING TOPICS AND DATES

MEETING DATE	TOPIC	FACILITATOR
1 - 24/3/2021	Overview and Decide on Roles	Selected group leaders
2 - 21/4/2021	General Care and Disease Management	Invited Community Health workers
3 - 19/5/2021	Wound Care	Invited Community Health workers
4 - 23/6/2021	Vocational Training / Skills Acquisition	Local government skill acquisition department
5 - 28/7/2021	Social Skills	LGA, supported by Research Team

AGENDAS FOR GROUP MEETINGS AT DISTRICT LEVEL - 5 MONTH SCHEDULE

WEEK 1: INTRODUCTION AND OVERVIEW OF SUPPORT GROUPS FACILITATED BY RESEARCH TEAM AND CO-RESEARCHERS

PROCESS	DURATION
Opening prayers	2 minutes
Introductions	5 minutes
Overview of the support group, confirm roles and responsibilities, membership fee and topics of agendas	90 minutes
Break	5 minutes
Discussions and any other business	20 minutes
Closing prayer	2 minutes
Complete baseline surveys after meeting	

**WEEK 2: GENERAL CARE
FACILITATED BY HEALTH WORKERS**

PROCESS	DURATION
Opening prayers	2 minutes
Introductions	5 minutes
General care	80 minutes
Break	10 minutes
Discussions from last meetings and any other business	30 minutes
Closing prayer	2 minutes

**WEEK 3: HEALTH CARE/WOUND CARE
FACILITATED BY HEALTH WORKERS**

PROCESS	DURATION
Opening prayers	2 minutes
Introductions	5 minutes
Health talk on wound care	80 minutes
Break	10 minutes
Discussions from last meetings and any other business	30 minutes
Closing prayer	2 minutes
Complete mid-point surveys after meeting	

**WEEK 4: VOCATIONAL TRAINING/SKILLS ACQUISITION
FACILITATED BY LOCAL GOVERNMENT SKILL ACQUISITION DEPARTMENT**

PROCESS	DURATION
Opening prayers	2 minutes
Introductions	5 minutes
Vocational training	80 minutes
Break	10 minutes
Discussions from last meetings and any other business	30 minutes
Closing prayer	2 minutes
Complete mid-point surveys after meeting	

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