



NETHIPS

**Network of HIV Positives
in Sierra Leone**

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HANDBOOK FOR NETHIPS AFFILIATED SUPPORT GROUPS

OVERVIEW

What is a support group?

NETHIPS support group is a community based association of people living with HIV, who get together through regular interactions like meetings to discuss but also provide psycho social support through peer to peer mechanisms. The groups are forum in which members can share problems and concerns, brainstorm solutions, give each other advice and form friendships.

NETHIPS affiliated groups are at different levels of evolution and are classified into associations and community based groups depending on the achievement over time.

Some of the members of the support groups serve as community volunteers commonly known as Community Healthcare Workers (CHW), Expert clients, Peer Educators or Defaulter Tracer. This role attracts different assignments that connect community to facility and verse versa. The engagement of the volunteers therefore has a spill over effect to support group socially and economically.

Why do People Living with HIV join support groups?

Joining a Support Group has the following benefits.

- Members have an opportunity to share experience on their journey on treatment which reduces anxiety for those newly diagnosed.
- These being informal meeting, provides an opportunity to be listened to and the eventual emotional healing.
- Adoption of desired behaviour like disclosure and condom use can be demonstrated for easy understanding
- Joining Support Group instils the sense of belonging and togetherness amongst PLHIV.
- It's a structure for capacity building, learning and ongoing mentorship.
- It reinforces the determination to live long productive life

Living positively with HIV

The recruitment of PLHIV to the support group has helped to instil hope among members but also the live testimony on the journey on treatment.

In the support groups treatment challenges and options are shared as living examples and members have an opportunity to ask and get responses to their concerns thus better manage themselves moving forward.

Disclosure

The disclosure formed part of the training modules to support groups but also the individual testimonies from the members on how they did it are the biggest source of inspiration to the members. Disclosure forms a critical part in client care and treatment and therefore the support to this is always prioritised. In this, members are guided on who to disclose to, when, how and why to disclose as motivation approach to ease the process rather than the members imagining how to go about it.

Relationships

Members are observed to respect one another as these are peer to peer discussions of mutual respect. Contribution to a particular agenda item encourages the submission of the seen to be quiet members for their views. The circle sitting arrangement during support groups meetings encourages face to face discussion for easy sharing of information and demystifying power relationship among members.

Support groups are encouraged to organize and conduct exchange visits among themselves as way of promoting learning.

Stigma

The routine organizing and attendance of support group meetings by members have helped in the mitigation of stigma. These groups have also been supported with information on stigma reduction through trainings and ongoing monthly support group supervision. They also sing loud as a sign that those who meet have accepted their status and are willing to interact.

Guidelines

It is important to understand the basic principles that underpin the operation of successful support groups. This booklet articulates these

basic guidelines for stakeholders interested in the information on the operationalisation of a support group. The status and understanding of how these association or community based organisation go about their day to day operations.

All NETHIPS affiliated support groups have documented guidelines that support the support group leaders (executive) use for governance of the support group. The associations or community based organisations for PLHIV as defined by the different criteria of establishment.

Annexed in this document are support documents that are helpful in the description of the different key result areas.

Activities

On a regular basis, group members work together to develop activity plan. The groups register membership for both new and old in every sitting which practice is aimed at bridging the gap between clients in care and those who are in the support groups. They routinely have visits from NETHIPs project team to beef up and clarify on emerging concerns.

Best Practice

1) The group do documentation for the monthly activities but also conduct exchange visit to other support group. The visits are for learning and sharing experiences.

2) The support groups are continuously working with the area health facilities for strategic reasons and some of the members actually offer ART counselling. The expert clients therefore are part of the structure to the national response and are sources of recruitment of new members into the support group.

Ledger for Registration

The guidelines are grouped under five main headings:

General

Joining Support Group

Operations and Logistics

Activities

Best Practice

Groups for Specific Populations of PLHIV

General

1) PLHIV meaningfully participate in all aspects of support group formation and operation.

Although NGOs, CBOs and health facilities often play a role in forming, nurturing and facilitating support groups, the primary drivers and decision-makers are the support group members to create group ownership towards sustainability.

Support group leaders (executive) ensure meaningful participation by support group members through: Decisions in the support group are collectively made by members to create ownership over the group,

Support group members understand that the group's success is dependent upon their own interest and active participation.

2) Support groups create a safe environment for members to share on positive living including coping mechanisms in confidence. As such support group members must uphold confidentiality at all times.

Support group members must be certain that any information they share with the group will not be discussed outside group boundaries without their consent. The success of the support group is dependent on members trusting each other, which then facilitates free, open discussions.

It is the responsibility of support group leaders (executive) to ensure that confidentiality is upheld by all members through:

- Sensitizing all support group members on confidentiality
- Being role models on confidentiality and trust
- Ensuring that this concept is clearly defined and documented in support group constitutions and members agree collectively on sanctions applicable to members who do not uphold confidentiality.

One way to promote confidentiality is for members to sign a ‘confidentiality agreement’ that commits them to upholding confidentiality. Group guidelines/bye-laws/constitutions can also be developed to guide the code of conduct within PLHIV support groups.

Forming Support Groups

1) Every support group should have a constitution, **developed by its members**, that clearly outlines how the support group will function.

Constitutions provide clear guidance about what is allowed and what is not allowed within the group, and they establish the framework for the group’s norms and values.

At a minimum, association/support group constitutions should address:

- Objectives and activities of the support group (Reasons why the support exists)

- Membership (e.g. who can be a member, how new members will be recruited; minimum number of members to establish the support group; membership fee, if any)
- Coverage (location of support group, locality from which members come from/catchment area) Rights and responsibilities of group members
- Confidentiality-expectations from members and leaders, sanctions for not upholding confidentiality
- Conflict resolution and grievance procedures (e.g., what happens if a member does not abide by the agreed rules governing the group)
- Leadership (positions and their responsibilities, selection-criteria, how to select the leaders, how to replace leaders (positions that fall vacant before the stipulated term is over), term office and)
- Meeting (frequency, time, venue, different types of meetings eg adherence counselling, livelihood support meetings, documentation, mobilization)
- Review of the constitution (how to make review suggestions, process of reviewing and documentation of amendments),

Having a constitution that all group members are aware of and believe in provides the foundation for teamwork and smooth operations and reduces the potential for confusion and conflict.

2) Groups members must share common objectives and mutual values they believe in to enhance ownership and mitigate possible conflict.

3) Membership in support groups is voluntary.

Individuals are made to understand the purpose and vision of a particular support group; they decide whether or not they want to join. In discouraging duplication of resources and double-counting of members, PLHIV can join only one support group at a time. In addition, this means each member is fully committed as they will not be dividing their time between different groups. Each member is encouraged to actively participate in each group and the group must endeavour to meet the needs of its members. Before joining a group, PLHIV should not only consider how they might benefit from the group, but also how they will be able to contribute to the group to make it effective and efficient.

4) Support groups for PLHIV should only contain PLHIV.

While support groups are made up of members who are HIV-positive to allow for frank and open discussion, peer support etc., there are many ways that people who are HIV negative can support PLHIV. For example, in some communities' additional peer support groups have been formed comprising of guardian and mothers of HIV-positive children and the infected children. Similarly, individual community members serve as 'treatment buddies' for PLHIV who belong to support groups. Families of PLHIV, caregivers of orphans and vulnerable children, and other specific groups affected by HIV will be considered in forming their own support groups in which they share mutual problems and concerns, discuss solutions, give each other advice and form friendships.

5) Group leadership is selected through a process that is transparent and fair, as articulated in the group constitution.

Some support groups use a system of ‘rotational leadership’, whereby members move through leadership positions on a regular basis. Other groups use secret ballot elections to choose their leaders. Each method has its own strengths and weaknesses, which group members should carefully weigh.

6) The roles of group leadership are clearly defined. Support group leaders do not undertake unilateral decisions, rather, they build consensus and act as coordinators. Leaders’ roles involve:

- Ensuring all members actively participate,
- Upholding the group constitution,
- Organizing effective group meetings, and
- Overseeing the group’s schedule of activities.

7) A support group cannot meet all of the emotional, social, spiritual and health needs of PLHIV. At the group level, experience sharing is done for coping mechanism and identification of treatment complication is done to be able engage the required support. Drug stock outs and treatment side effects are reported before the situation escalates to avoid drug resistance.

8) There must be clear distinction between support groups and groups that work together on income-generating activities (IGAs). Not all support group have IGAs but where this happens, its voluntarily and not aligned to the role of the support group

Due to the economic burdens that PLHIV face, such as the cost of healthcare and transport to medical appointments, support group members sometimes decide to collaborate on IGAs. But when support groups engage in IGAs, their support focus can be compromised. In addition, people who are not HIV-positive may begin asking to join the

group. As one support group member said, “*Support groups are not about money issues; they are about giving each other emotional support to cope and about having a place where we are free to discuss our illness in a safe, non-judgmental atmosphere*”.

Operations and Logistics

1) The meeting venue needs to be accessible, affordable, safe to group members. Most of the support groups are closer and affiliated to the area health facilities and they routinely meet as per their agreed schedule. Members agree on the meeting time.

2) Members agree on the meeting agenda item and key issues to be discussed

3) Meeting facilitators come from inside and sometime outside the group. The outside facilitators are either health care workers or other program support staff. If the group wants to explore a topic and no member has the required expertise, the group look for qualified facilitators within other PLHIV support groups or request a facilitator from NETHIPS.

4) The group have established meeting ground rules. These rules are more specific than the constitution and include things such as agreeing to listen when others are speaking, respecting time, and supporting the participation of all members.

Appendix 1: About NETHIPS

Background

Established in 2006, the Network of HIV Positives in Sierra Leone (NETHIPS) is the umbrella organization for People Living with HIV (PLHIV) in the country. NETHIPS has a national office housed in the capital city - Freetown and 3 regional offices in Bo (Southern Region), Makeni (Northern Region) and Kenema (Eastern Region). In addition, there are at the moment 43 PLHIV community support groups nationwide with a spread across all regions and geographical districts in the country. The national office coordinates all the activities of the regions and the support groups, while each regional office plays oversight to the support groups in their respective regions. Support groups provide safety nets for PLHIV through experience sharing and promotion of positive living.

Owing to the huge impact of HIV on women living with HIV, the Voice of Women was established in 2007 as the arm of NETHIPS to respond to the specific needs of women and girls.

NETHIPS has been at the forefront of the HIV response since its establishment in 2006. NETHIPS aims to continue to play an active role in advocating for and ensuring the meaningful involvement and quality of life of PLHIV by transforming itself in order to meet the ever-growing needs and challenges of the HIV response. Informed by the vision to be a powerful, united national social movement of PLHIV, with their leadership and voice at the core of the HIV pandemic, NETHIPS recognizes the changing context of the HIV & AIDS response and therefore keeps evolving with the times to remain current and revolutionary.

Vision

A Sierra Leone in which all people living with HIV (PLHIV) and their dependents shall enjoy equal rights and opportunities and live productive, dignified and meaningful lives.

Goal

To advocate for the improvement in the quality of life of people living with HIV and to reduce the impact of HIV on the lives of those infected and affected by HIV in Sierra Leone.

Mission

To empower, strengthen and coordinate all support groups and organizations of people living with HIV in Sierra Leone to contribute meaningfully to the national response.

Motto

Working in partnership to eradicate the negative consequences of HIV in Sierra Leone

Objectives of the Organization

- i. To mobilize resources to implement programmes that seek to improve the lives and wellbeing of PLHIV and their dependents.
- ii. To advocate for improved access to and utilization of anti-retroviral drugs (ARV)

- including opportunistic infections drugs for all eligible PLHIVs and support adherence and retention on treatment.
- iii. To engage in empowerment and enterprise development activities that will improve the quality of lives of PLHIV and their dependents.
 - iv. To advocate for access to health and rights of PLHIV through the improvement of HIV-related policies, laws and practices that uphold Human Rights.
 - v. To facilitate the creation of new support groups and strengthen existing ones in every district with the view of discussing the health and psychosocial challenges experienced by PLHIV and best coping mechanism.
 - vi. To advocate for improved access to health for all PLHIV in Sierra Leone.
 - vii. To provide a platform for PLHIV in Sierra Leone to come together to exchange ideas and share experiences of living with HIV with less anxiety
 - viii. To give a “human face” and “voice” to the HIV & AIDS pandemic in Sierra Leone by ensuring meaningful representation and involvement of PLHIVs in relevant forums locally and internationally in line with UNAIDS GIPA and MIPA Principles
 - ix. To collaborate and strengthen cooperation with the Government of Sierra Leone and other relevant stakeholders including the UN Systems in the prevention and control of HIV and AIDS as well as care and support for PLHIV
 - x. To build and strengthen the capacity of the Network and that of its member constituencies (support groups) with adequate knowledge and skills to effectively deal with the HIV & AIDS pandemic

Core Values

- i. **Stewardship:** Good stewardship of resources, Honesty, transparency, and accountability in all our dealings
- ii. **Gender equality and equity:** affirmative action - action favouring qualified and competent PLHIV and women; positive discrimination
- iii. **Social Inclusion:** improving the ability, opportunity, and dignity of PLHIV
- iv. **Positive Health Dignity and Prevention (PHDP):** An unconditional, holistic and non-judgmental approach to care, support, treating every individual with the respect and dignity. Recognize and pursue the dignity and the right to quality life of PLHIV, A commitment to empowering and developing people to their optimum potential
- v. **Non-discrimination:** Personnel policies and practices that are just and non-discriminatory with proper regard to health, safety and equal opportunities
- vi. **Tolerance and Neutrality:** Maintain political, ethnic/tribal and religious neutrality and tolerance
- vii. **Fairness and Justice:** Participatory democratic decision-making processes
- viii. **Take collective** responsibility in decision-making

Appendix 2

MEMORANDUM OF UNDERSTANDING NATIONAL AIDS CONTROL PROGRAM (NACP) AND THE NETWORK OF HIV POSITIVES IN SIERRA LEONE (NETHIPS)

I. PURPOSE

The National AIDS Control Program (NACP) of the Ministry of Health and Sanitation (MoHS) and the Network of HIV Positives in Sierra Leone (NETHIPS) are concerned about the relationship of all HIV Positive clients receiving medical and/or psycho-social services by the Government of Sierra Leone and the access to NETHIPS support groups.

Therefore, wherever possible and mutually beneficial, NACP and NETHIPS will seek to collaborate on outreach to HIV Positive clients so they are able to get the care and support they deserve. This Memorandum of Understanding (MOU) sets forth the basic principles and guidelines under which the parties will work together to accomplish the goals of increasing access to services available in Sierra Leone for HIV Positive clients.

II. AUTHORITY

Both parties are represented in this agreement by their heads of institutions (NACP – Programme Manager and NETHIPS - Executive Director) that have the authority to enter into this partnership.

III. IMPLEMENTATION OF AGREEMENT

a. It is agreed that NACP will perform the following actions:

1. Counsel clients
2. Test clients
3. Treat HIV Positive clients
4. Refer clients to NETHIPS' Support Groups
5. Share data on clients as may be useful in proving needed support services
6. Provide all other services as will be determined by both parties

b. It is in agreement that it is the responsibility of NETHIPS to carry out the duties listed below:

1. Place HIV Positive clients into existing support groups
2. Establish support groups where they are not yet in existent and the need is great
3. Strengthen the existing support groups
4. Provide feedback to NACP on clients referred to support groups

c. NETHIPS shall coordinate the activities of all care and support groups with a view of strengthening them through: resource mobilization and funding, capacity building, advocacy for the support groups, and by monitoring activities of the groups.

- d. Representatives of NACP and NETHIPS shall meet on a quarterly basis to discuss and direct activities conducted under this MOU, along with any challenges or opportunities the parties are encountering.
- e. The parties share a common interest in improving the referral process and reproductive health care delivery systems to increase the availability and accessibility of services among PLHIVs in Sierra Leone.
- f. Both parties (NACP and NETHIPS) shall seek to resolve any dispute concerning this MOU through discussions in good-faith.
- g. Both parties (NACP and NETHIPS) will work towards developing consensus on the scope of services and participation; anticipated outcomes; roles and responsibilities and any appropriate and necessary aspects of mutual activities.

IV. EFFECTIVE DATE

This MOU is effective upon signature of both parties (NACP and NETHIPS) and will remain in effect unless and until terminated as provided under Article VI.

V. AMENDMENTS

This MOU may be modified or amended by written agreement between both parties. Additionally, any terms or conditions involving NACP and NETHIPS not stated in this MOU but expressly agreed to in a future MOU signed by both parties is considered integrated into this MOU.

VI. TERMINATION

This MOU will expire sixty (60) months from the date of execution must be renewed by mutual agreement of both parties. This MOU may be terminated at any time by mutual agreement of both parties. Expiration or termination would affect only pursuit of new project under the MOU. Projects under way will be governed by the specific individual agreements anticipated above.

AGREED TO BY:

 Mr. Idrissa Songo
 (Executive Director)
 Manager)
 Network of HIV Positives in Sierra Leone
 Control Program
 114 Pademba Road
 Freetown, Sierra Leone

Dr. Momodu Sesay
 (Programme
 National AIDS
 Connaught Hospital
 Freetown, Sierra Leone

On this date _____
 date _____

On this

Appendix 3

**MEMORANDUM OF UNDERSTANDING BETWEEN
NETWORK OF HIV POSITIVES IN SIERRA LEONE (NETHIPS)
AND SUPPORT
GROUP THAT IS LOCATED IN
.....
..... IN THE
..... PROVINCE OF SIERRA LEONE**

Introduction

Networking is a process by which two or more organizations collaborate to achieve common goals.

Networks which adhere to the constitution of the West-African Network of People living with HIV/AIDS (NAP+/WA) are formed in various West-African countries.

NAP+/WA are the West-African Sub-Regional Committee of the Network of African People Living with HIV/AIDS (NAP+).

NETHIPS being the Sierra-Leonean chapter is bringing together all the national Associations of People Living with HIV and AIDS in the country to:

- better coordinate care and support activities
- advocate on behalf of PLHIV

PURPOSE OR MISSION OF NETHIPS

- To act as a national co-ordinating body for all PLHIV care and support groups in Sierra Leone working in line with the National AIDS Secretariat (NAS)
- To build the capacity of the care and support groups of PLHIV in Sierra Leone
- To advocate for the recognition of the rights of people living with HIV (PLHIV) in Sierra Leone

This Memorandum of Understanding (MOU) sets forth the basic principles and guidelines under which the parties will work together to accomplish the goals of increasing access to services available in Sierra Leone for HIV Positive clients.

VII. AUTHORITY

Both parties are represented in this agreement by their heads of institutions (NETHIPS - Executive Director and Support Group -head of the Support Group) that have the authority to enter into this partnership.

VIII. IMPLEMENTATION OF AGREEMENT

- h. It is agreed that Support Groups will perform the following actions:
- i. Affiliated support groups are encouraged to work with other non-governmental organizations (NGOs), religious/faith based organizations and other organizations for the purpose of improving their operational effectiveness

- ii. Each support group will continue to enjoy its independence and maintain its members and its ideals as a support group in line with standard operating procedures developed and endorsed by NETHIPS
 - iii. Each support group shall encourage its members to actively participate in all activities organized by NETHIPS wherever and whenever possible
 - iv. Support Groups will receive and register clients that have tested positive to HIV for membership
 - v. Only HIV positive clients within a support group and their HIV-related orphans/vulnerable children will be members of NETHIPS. Other members of support groups that are not HIV positive are not members of NETHIPS
 - vi. Support groups affiliated to NETHIPS shall provide monthly report to NETHIPS
 - vii. Support groups affiliated to NETHIPS shall be discouraged to work with organizations that NETHIPS feel are not working in its interest.
- i. It is in agreement that it is the responsibility of NETHIPS to carry out the duties listed below:
- 5. Place HIV Positive clients into existing support groups
 - 6. Establish support groups where they are not yet in existent and the need is great
 - 7. Strengthen the existing support groups
 - 8. Represent PLHIVs in Sierra Leone
 - 9. NETHIPS shall coordinate the activities of all care and support groups with a view of strengthening them through: resource mobilization and funding, capacity building, advocacy for the support groups, and by monitoring activities of the groups.
 - 10. Provide a platform for PLHIVs in Sierra Leone to come together to exchange ideas and share experiences of living with HIV with less anxiety
 - 11. Act as the official advocacy platform for PLHIVs in Sierra Leone

IX. EFFECTIVE DATE

This MOU is effective upon signature of both parties (NETHIPS and Support Group/Approved Representative) and will remain in effect unless and until terminated as provided under Article VI.

X. AMENDMENTS

This MOU may be modified or amended by written agreement between both parties. Additionally, any terms or conditions involving this Support Group and NETHIPS not stated in this MOU but expressly agreed to in a future MOU signed by both parties is considered integrated into this MOU.

XI. TERMINATION

This MOU will expire sixty (60) months from the date of execution must be renewed by mutual agreement of both parties. This MOU may be terminated at any time by mutual agreement of both parties. Expiration r termination would affect only pursuit of new project under the MOU. Projects under way will be governed by the specific individual agreements anticipated above.

XII. OTHER CONSIDERATION

Both parties acknowledge, consent, agree and stipulate that this agreement in no way creates an employee/employer relation between NETHIPS and affiliated support group and therefore does not obligate NETHIPS to provide any benefits or payment other than those specifically approved by both parties before the execution of any project/s.

The agreement does not create any obligation-legal, financial or otherwise-other than that stipulated herein, to any persons claiming entitlement to compensation or other remedies related to personal injuries, economic harm, or otherwise, either before, during or after the execution of this agreements.

AGREED TO BY:

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Freetown, Sierra Leone.

(Support Group Head)

Address:

Tel:

On this date _____

On this date _____