# Facilitation Guide for Community-Based Groups

## Practical step-by-step facilitation guidance for front-line implementors of groups formed by people affected by skin-NTDs

(Companion resource to the Implementation Manual for Community-Based Groups)



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Practical step-by-step facilitation guidance for front-line implementors of groups formed by people affected by skin-NTDs

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The recommendations presented in this publication are based on evidence and learning from the UPLIFT study and may need to be adapted to local contexts, policies and health systems. They do not necessarily represent the official views of all consortium partners or the funding organization.

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# INTRODUCTION

## 1.1 Community-Based Groups: Rationale and Purpose

In settings where health systems face constraints in addressing the long-term needs of people affected by skin-NTDs, Community Based Groups (CBGs) offer an important community-level platform to complement formal services, support continuity of care, and strengthen accountability. Beyond this supportive role, CBGs can act as a vehicle for enhanced ownership and empowerment, contributing to improved social participation, reduced stigma, improved mental wellbeing, and financial sustainability. For these reasons, CBGs are increasingly promoted within the strategic framework of the World Health Organization (WHO) for the integrated control and management of skin-related neglected tropical diseases (skin-NTDs) to advance both people-centred care and progress towards elimination targets.

Launched in 2023, the UPLIFT[1] study set out to address a common problem: organisations running CBGs for people affected by skin-NTDs had no shared framework to guide how these groups should operate. The study aimed to define the core components of a harmonized CBG model, bringing together self-care, psychosocial support and participatory group practices. The Implementation Manual and Facilitation Guide are two of the end products of this work.

## 1.2 Purpose and Use of the Facilitation Guide

This Facilitation Guide is a practical resource for implementers and frontline workers supporting CBGs among communities affected by NTDs where there is a need for ongoing care. It builds on the Implementation Manual for Community Based Groups and serves as a companion document, providing a clear, ready-to-use operational plan for integrated skin-NTD CBG development.  Figure 1 outlines the differences in purpose and use between the two documents.

*[1] Unlocking the Potential of Leprosy & NTD affected people, to pursue Inclusive, Fulfilling and Transformational lives*

| | Implementation Manual | Facilitation Guide |
|---|---|---|
| Purpose | » Recommendations on WHAT should be done | » Indications on HOW to implement key recommendations |
| Guidance | » Strategic<br>» Programmatic | » Step-by-step guidance<br>» Facilitation toolkit |
| Main content | » Core principles<br>» Development stages<br>» Milestones<br>» Roles and safeguards | » Meeting structure<br>» Facilitation techniques<br>» Resources and tools<br>» Practical exercises |
| Main users | » Those planning, supervising or evaluating CBG programmes | » Those directly implementing or facilitating CBG sessions |
| When used | » Programme planning and monitoring<br>» Training<br>» CBG model adaptations | » Before and during facilitation of CBG meetings |

**Figure 1 : Purpose and use of the Facilitation Guide**

The guide presents a structured methodology on “How” to implement the Implementation Manual for Community-Based Groups, from group inception and capacity strengthening to active participation in NTD programming, supporting the gradual building of skills, ownership, and autonomy.

The approach is organized into three stages across 12 monthly meetings following the conceptual framework of the UPLIFT CBG model (figure 2). However, we recognize that community development is not a linear process and should not be time-bound; the stages are intended as flexible guidance rather than fixed steps. Implementers should adapt the methodology to the local context, needs, and pace of each group. The overall aim is to integrate evidence-based touchpoints that establish the foundations for CBGs to address their own needs and participate meaningfully in society.

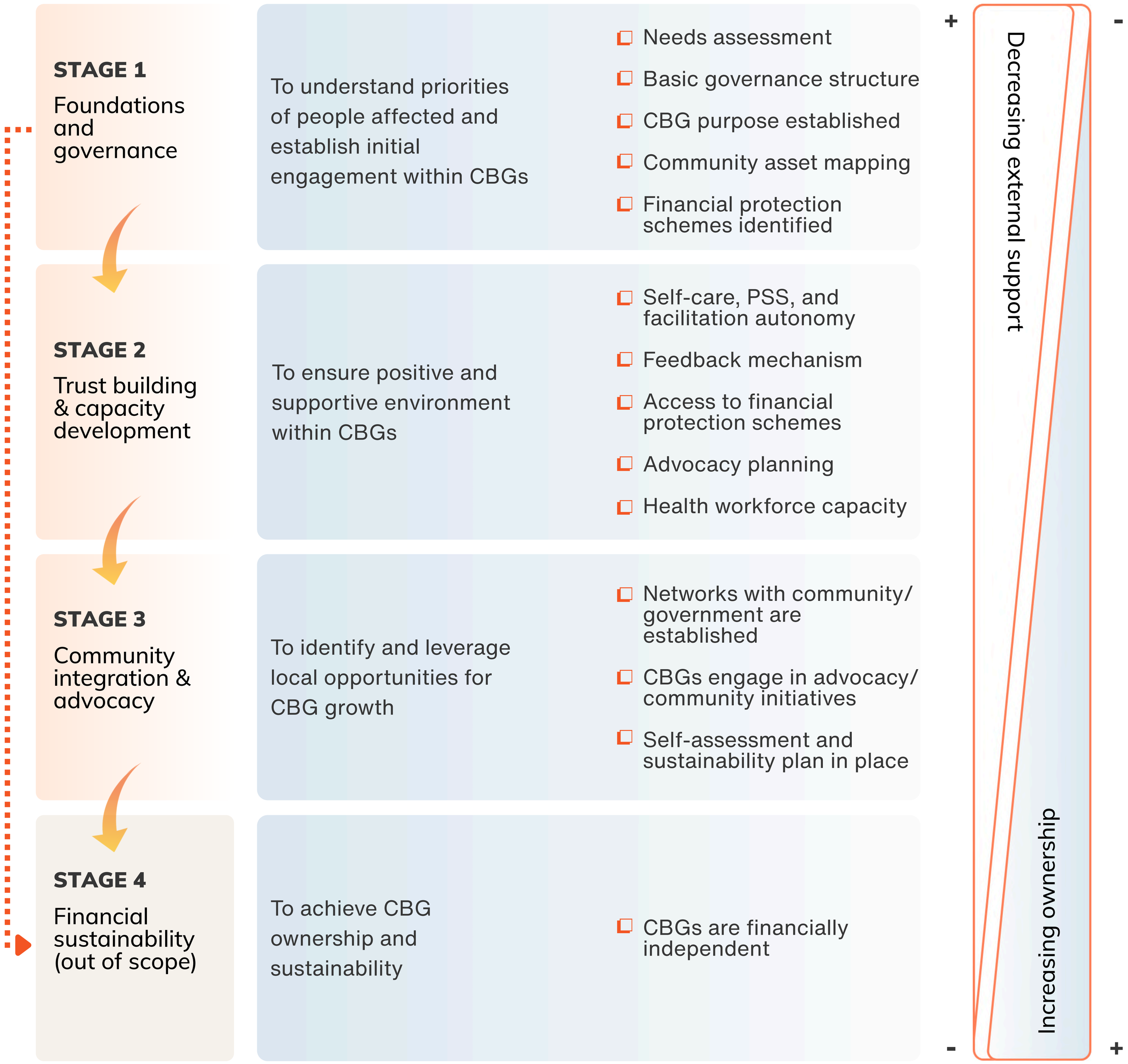



*Figure 2: Conceptual framework of the UPLIFT CBG model*

The scope of CBG development is framed within the UPLIFT three-stage approach. More advanced stages of community evolution, including complex leadership transitions, deeper shifts in group dynamics, broader advocacy engagement, multi-level partnerships, or scaling impact beyond the local level, are not covered in detail in this guide. The section titled “Stage 4: Financial Sustainability of CBGs” within the Implementation Manual provides practical guidance to help groups maintain momentum, adapt to changing contexts, and continue functioning effectively beyond the timeframe and structure outlined here. Although framed under Stage 4, sustainability is addressed from the outset. However, long-term sustainability is influenced by multiple contextual and organisational factors and therefore extends beyond the scope of this guide.

# 2 GROUP FACILITATION CONSIDERATIONS

## 2.1 Meeting Characteristics

This guide recommends monthly meetings as the primary implementation modality of the UPLIFT model. The following meeting considerations are proposed to support consistency, participation, and overall effectiveness:

- Duration and Frequency
  Each session should last approximately 2-3 hours, allowing sufficient time for meaningful discussion, participatory activities, and reflection without overburdening participants.

- Location and Accessibility
  Meetings should be held in a safe, convenient, and easily accessible location, ideally within walking distance for participants (including for those with mobility challenges). This helps promote regular attendance and inclusion, particularly for those with mobility or financial constraints.

- Group Composition
  A typical CBG should include 10–15 participants. Gender representation should be balanced and adapted to the local context, so all participants feel comfortable contributing. Meetings should generally be held jointly, with separate sessions used where appropriate, such as for NTDs affecting the genitalia (e.g. hydrocele). Where possible, it is recommended that at least two members have writing and reading skills, to support the group's transition to independent ownership and reduce long-term dependency.

## 2.2 Suggested Meeting Flow

To maintain consistency and focus, each meeting should follow a simple structure:

| | |
|---|---|
| **Orientation/Progress Review (15 min)** | Begin with outlining the content of the session. This is also an opportunity for review of previous actions, allowing members to share updates, challenges, and achievements. |
| **Core Activities (1-2 hours)** | Engage participants in key thematic areas, which may include:<br>☐ Self-care practices<br>☐ Psychosocial support (PSS)<br>☐ Advocacy initiatives<br>☐ Community engagement efforts |
| **Action-Oriented Wrap-Up (15 min)** | Conclude with a clear summary of key takeaways and agree on practical next steps or actions. This ensures that each session leads to tangible progress and reinforces accountability within the group. |

## 2.3 Facilitation as a Phased Handover

Facilitation should be seen as a fluid, phased process (Figure 3), gradually handing over responsibility to elected leaders and peer supporters as CBG facilitators. External facilitation may be more intensive during group formation, supporting the establishment of structured governance; beyond this stage, external input should shift towards lighter-touch support alongside ongoing capacity development. The ultimate aim is for CBGs to become fully owned and autonomously facilitated by their leaders and peer supporters. This process should be made clear to all parties from the outset, to manage expectations and strengthen sustainability.

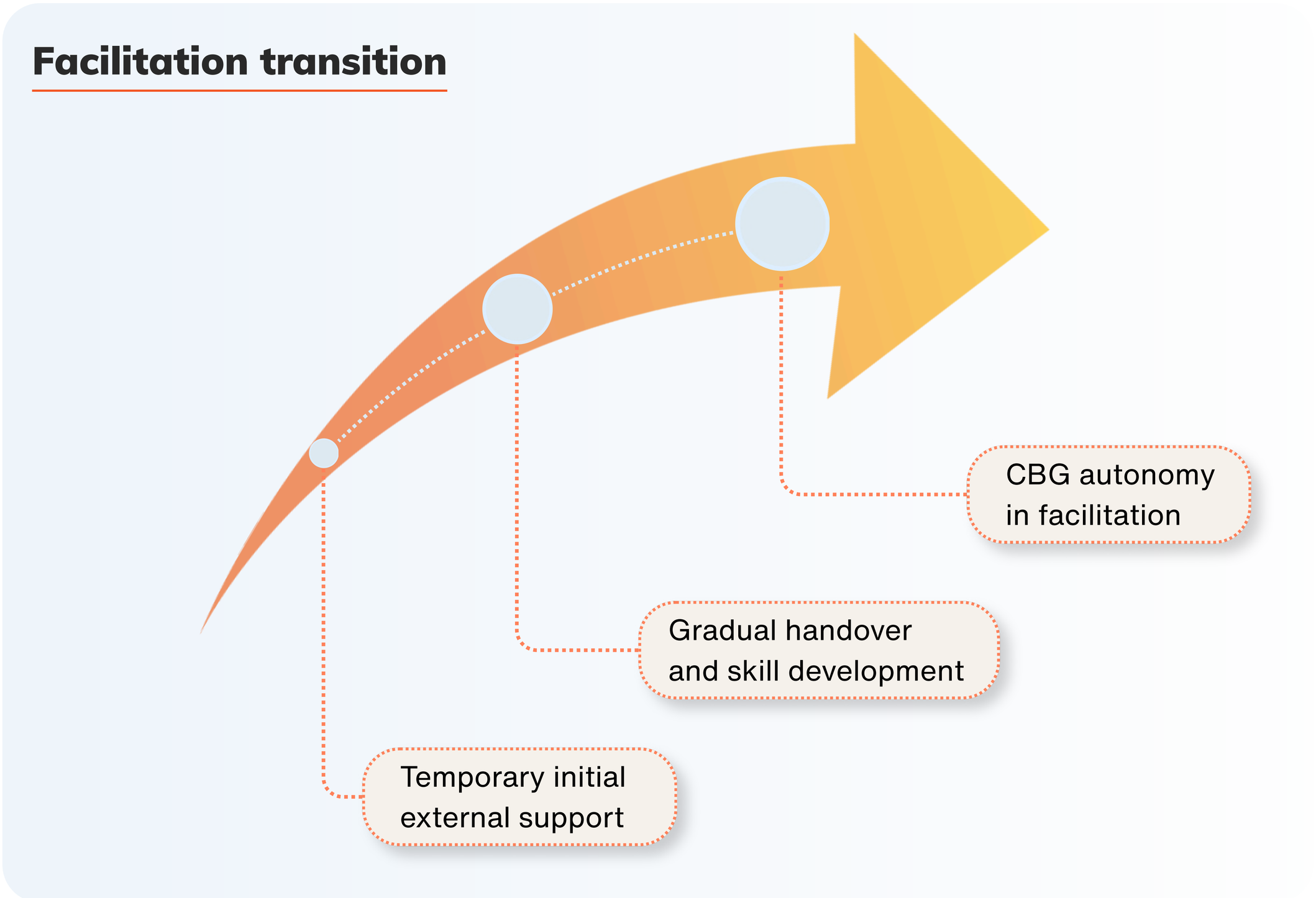



*Figure 3: Facilitation transition process*

## Temporary initial external support:

The following HR structure (Figure 4) is recommended to support effective operationalisation of the UPLIFT model during the initial implementation stages, when external technical support requirements are highest:

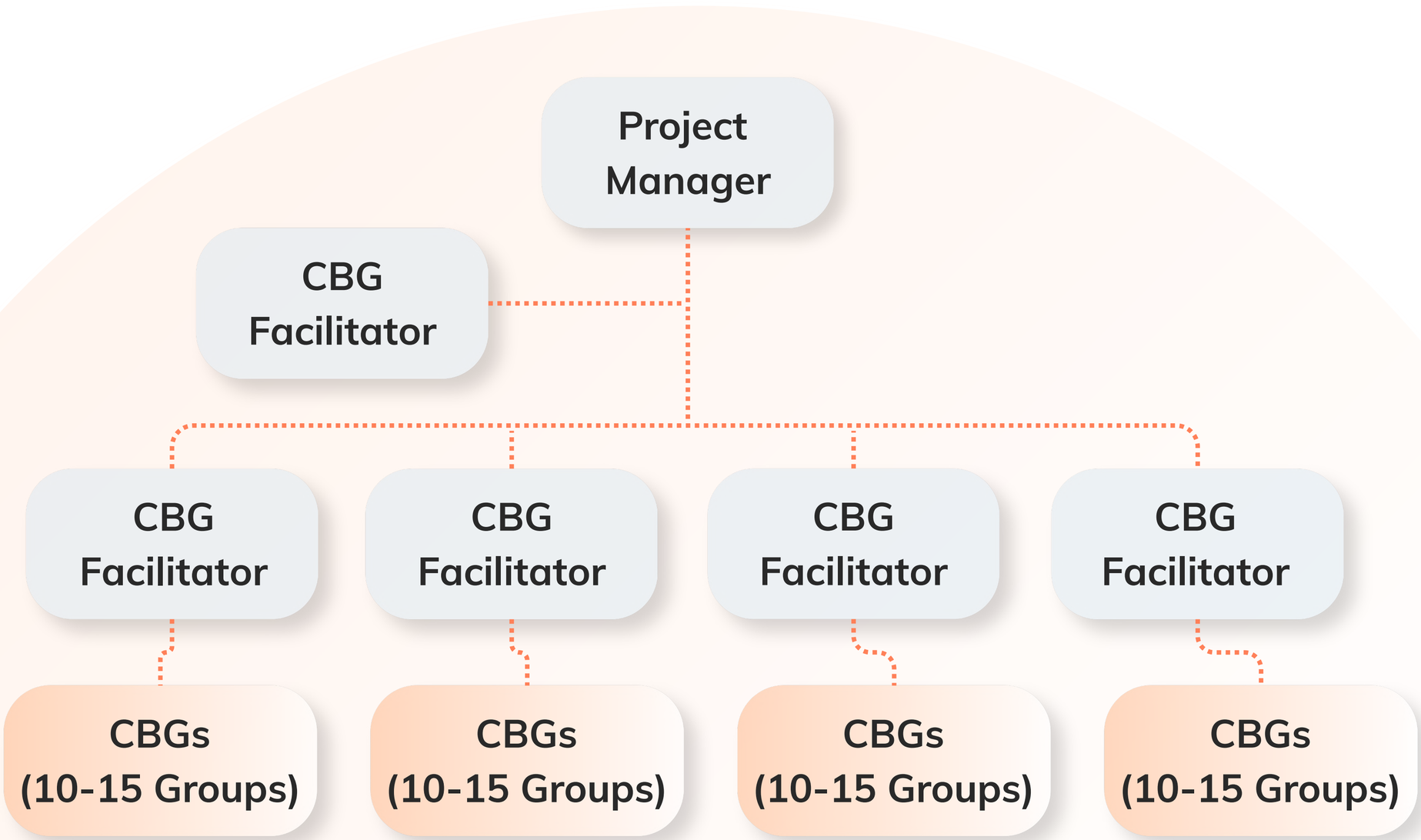



*Figure 4: Initial support structure for CBG Facilitation*

Each group should be supported by a CBG Facilitator, who is responsible for coordinating and delivering the monthly sessions.

### CBG Facilitator Selection Criteria

- Local, trusted, motivated
- Trained peer preferred, where available
- Otherwise: trained NGO volunteer, NGO staff or local government staff
- Supervision and training provided
- Buy-in from the community secured

To ensure quality engagement and adequate preparation, each facilitator should oversee a maximum of 10–15 groups, enabling each CBG to meet once per month. CBG Facilitators are supported and supervised by a CBG Coordinator, who leads on training, provides ongoing mentorship, and maintains linkages with relevant local stakeholders. Overall project implementation, including coordination and financial management, is overseen by a Project Manager, ensuring alignment with programme objectives and budget.

## Gradual Handover and Skill Development

Sessions are initially guided by a CBG facilitator, who supports group formation, builds confidence, and introduces core concepts. During this stage, responsibility should gradually transition to a CBG leader, strengthening local ownership and sustainability. The recommendations below are intended to support facilitators in facilitating CBG sessions effectively.

### Do's

- ✔ Provide close and consistent support during the initial stage, gradually handing over responsibilities as the group builds confidence and capacity
- ✔ Clearly communicate from the outset that facilitation is temporary, with the aim of CBGs independently leading their own meetings
- ✔ Develop strong core competencies in skin-NTDs, self-care practices, footwear measurement, and psychosocial support (PSS)

### Don'ts

- ✘ Avoid taking responsibility for functions that can be autonomously managed by CBG members
- ✘ Refrain from dominating discussions or decision-making; ensure all members have space to contribute
- ✘ Avoid excluding quieter or more vulnerable members from participation
- ✘ Do not create dependency on the facilitator; encourage group ownership of activities

## Do's

- Build a thorough understanding of the local context, including community dynamics and needs.
- Apply participatory approaches to promote shared decision-making and ownership
- Demonstrate strong skills in assertive communication, safeguarding, and conflict resolution
- Encourage the use of locally available resources and existing community strengths to support sustainable activities
- Ensure group activities are well documented internally as well as for project monitoring, evaluation, accountability and learning (MEAL) processes

## Don'ts

- Avoid overlooking local knowledge and community perspectives
- Do not rush the process. Capacity and confidence require time to build
- Refrain from ignoring power dynamics, safeguarding concerns, or conflicts within the group
- Avoid introducing or relying on external resources that the group cannot realistically maintain after project support ends

## CBG autonomy in facilitation:

The ultimate aim is for CBG facilitation to be led autonomously by CBG members - specifically, elected leaders and/or peer supporters - with external facilitator involvement reduced to monitoring and technical support as required. Additional context-specific support may be provided by other stakeholders, such as community health workers or local leaders, to address group-specific needs (Figure 5).

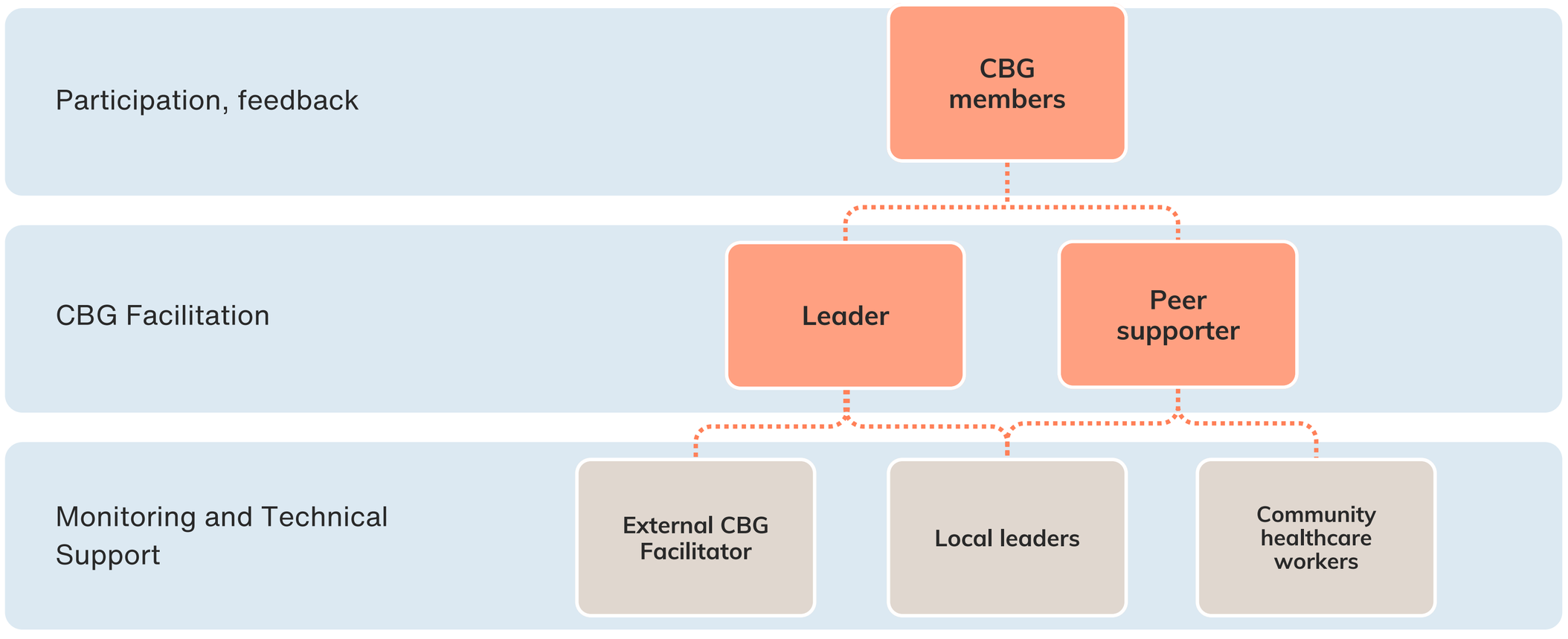



*Figure 5: Autonomous CBG Facilitation*

Specific roles and responsibilities for leaders and peer supporters relevant to CBG facilitation are outlined in the following table:

| Leader's Role | Peer Supporter's Role |
| --- | --- |
| Facilitate meetings, following agenda items<br><br>Promote open communication<br><br>Foster a supportive environment by encouraging members to exchange experiences and concerns, and by encouraging positive attitudes and self-care behaviours<br><br>Foster the exchange of challenges and barriers related to self-care practice in liaison with peer supporters<br><br>Coordinate activities with selected peer supporters<br><br>Write minutes after each meeting in coordination with note-takers<br>Liaise with NGO staff for guidance, reporting and support | Facilitate basic psychosocial support during monthly meetings, aiming to primarily address the mental wellbeing, the social sphere and the overall quality of life of CBG members.<br><br>Coordinate with group leader and NGO coordinators to ensure holistic approach and support<br><br>Spend time with other CBG members, sharing feelings and providing emotional support<br><br>Foster exchange of challenges and barriers related to self-care practice, in liaison with group leaders<br><br>Foster open conversations and regular experience sharing as a form of talk therapy<br><br>Support CBG members experiencing mental health conditions and/or psychosocial disabilities in accessing and navigating health services and other systems that address the broader determinants of wellbeing.<br><br>Refer those in need to professional services (hospital) |

## 2.4 Material Assets Provision

This Facilitation Guide includes activities that require material assets to be arranged before initiation of meetings. The list below provides a list of materials/assets that would support the UPLIFT Model roll out:

| Category | Asset list |
|---|---|
| **Stationery** | - CBG notebook<br>- Pens<br>- Flipcharts for participatory activities<br>- List of emergency contacts<br>- Health education materials for training sessions |
| **Selfcare materials*** | Selfcare kit including:<br>- Soap<br>- Oil<br>- Buckets and jugs<br>- Towel<br>- Gauze<br>- Antifungal cream<br>- Antibiotic ointment |
| **Protective footwear** | - Protective footwear (sourced externally)<br>or;<br>- Footwear production materials (rubber, glue, leather)<br>- Foot measurement materials<br>- Workshop equipment (grinder, sewing machine, hand tools) |
| **Aids and appliances** | - Crutches<br>- Sunglasses<br>- Wheelchairs/ mobility aids |
| **Identification/Recognition** | - Badges for group leaders, peer supporters |
| **Awareness raising materials*** | - Flyers<br>- Banners<br>- Leaflets |

** These may be provided at the outset to motivate members to engage initially, or where such materials are not readily available locally. Where possible, however, it is preferable to encourage the use of locally available resources.*

# 3. MONTHLY OPERATIONAL PLAN

## Stage 1: CBG Foundations and Governance

**Main Objective:** To establish the foundations for newly formed or early-stage CBGs, through participatory needs assessment, collective purpose-setting, basic governance structure, and early community linkage planning, for progressive capacity development and long-term sustainability.

**Stage 1 Milestones:**

| | | |
|---|---|---|
| 1 | Needs assessment completed | ☐ |
| 2 | Collective CBG purpose established | ☐ |
| 3 | Basic governance structure established | ☐ |
| 4 | Community asset mapping completed | ☐ |
| 5 | Financial protection schemes identified | ☐ |

**Duration:**
3-4 months

**Frequency of meetings:**
Once a month (3 meetings in total)

**Target Audience:**

- CBG facilitators (NGO staff)
- CBG members
- CBG leaders
- Peer supporters

# Month 1: Needs Assessment, Purpose and Self-Care Training

**Specific Objectives:**

- Ensure members understand that the group's goal is empowerment through shared decision-making.
- Support members to identify and prioritise their short-, medium-, and long-term needs.
- Facilitate a participatory process to define clear, needs-based group objectives.
- Introduce basic self-care practices for skin-NTDs.

| Core Activities | Description | Facilitator | Guiding Material |
|---|---|---|---|
| **Progress Review (10 min)** | • Welcome participants and facilitate introductions<br>• Explain the CBG's main functions and specific objectives of the session | CBG Facilitator | |
| **Needs Assessment (1 hour)** | • Assist CBG to identify their immediate needs<br>• Assess interest in formal registration and willingness for community engagement | CBG Facilitator | Appendix 1 |
| **Co-define Common Purpose (15 min)** | • Assist CBG to define short-, mid-, and long-term objectives and purpose<br>• Set a review timeline (4 months) | CBG Facilitator | Appendix 2 |
| **Self-Care Training (1 hour)** | • Support affected persons to practice self-care independently (with caregiver or family support where needed)<br>• Provide disease-specific health education<br>• Ensure all CBG members have access to necessary resources<br>• Arrange provision of footwear and aids and appliances | CBG Facilitator | Section 4. Training Resources (4.1 Self-Care) |
| **Action-Oriented Wrap-Up (5 min)** | • Review and document agreed actions in CBG notebook<br>• Briefly clarify logistics and explain topic of next meeting | CBG Facilitator | |

## Month 2: Governance and Self-Care Autonomy

**Specific Objectives:**

- Set up CBG governance by selecting leaders and peer supporters and defining member inclusion.
- Establish group rules, values, and meeting logistics for fair and organized operations.
- Strengthen group members' autonomy and confidence to independently manage and sustain their self-care practices.

| Core Activities | Description | Facilitator | Guiding Material |
|---|---|---|---|
| **Progress Review (10 min)** | • Review the minutes from the previous meeting<br>• Discuss current issues faced by members and identify practical solutions together | CBG Facilitator | |
| **Establish Governance Structure (45 min)** | • Assist CBG to set their inclusion criteria (15min) | CBG Facilitator | Appendix 3 |
| | • Assist CBG to define Ethics/Code of conduct (10min) | | Appendix 4 |
| | • Assist CBG to select leader and peer supporter (15 min) | | Appendix 5 and Appendix 6 |
| | • Assist CBG to agree on meeting logistics (5 min)<br>• Agree on a fixed meeting venue, date, and time<br>• Consider: Privacy, accessibility, seasonality, children´s participation | | |
| **Self-care Training Session (1 hour)** | • Reinforce learning topics from session 1 and encourage leader/Peer supporters to co-facilitate session<br>• Ensure all CBG members have access to necessary resources<br>• Provide footwear and aids and appliances as needed | CBG Facilitator with support from CBG leader and peer supporter | Section 4. Training Resources (4.1 Self-Care) |
| **Action-Oriented Wrap-Up (5 min)** | • Review and document agreed actions in CBG notebook<br>• Briefly clarify logistics and explain topic of next meeting | CBG Facilitator | |

# Month 3: Establishing Local Linkages and Introducing Basic Psychosocial Support

**Specific Objectives:**

- Enable CBG members to identify local community resources and key stakeholders that can support the group's purpose.
- Plan short-term actions to build linkages with identified resources for ongoing community engagement.
- Introduce Basic Psychosocial Support principles.
- Create a community-level referral pathway and build capacity for peer-support over time.

| Core Activities | Description | Facilitator | Guiding Material |
|---|---|---|---|
| **Progress Review (10 min)** | • Review the minutes from the previous meeting, including progress on agreed action points<br>• Discuss current issues and challenges faced by members and identify practical solutions together | CBG leader | |
| **Community Asset Mapping Workshop (1.5 hours)** | • Assist CBGs to identify resources in their community using participatory methods and plan for short-term actions, including the creation of linkages with identified resources<br>• Consider resources which can help achieving the CBG´s purpose and future community engagement | CBG facilitator | Appendix 7 |
| **Basic Psychosocial Support (PSS) (1 hour)** | • Focus on non-professional support for improving mental wellbeing, social connections, and overall quality of life<br>• Provide PSS through trained facilitators who encourage open discussions about mental wellbeing, awareness around signs and symptoms and influencing factors<br>• Map available mental health services and establish a community-level referral pathway<br>• Begin with NGO-led PSS, then train peer supporters as the group matures | CBG Facilitator with support from CBG leader and peer supporter | Section 4. Resources (4.2 PSS) |
| **Action-Oriented Wrap-Up (5 min)** | • Review and document agreed actions, briefly clarify logistics and explain topic of next meeting | CBG leader | |

## Supporting Activities (Stage 1)

**1. Leadership Training:**

- Equip CBG leaders with skills in communication, advocacy, co-design, decision-making, conflict resolution, governance and effective local representation.
- Provide information and linkages to local resources that can support the group's needs.
- Use role plays and interactive exercises to simulate real-life scenarios and build practical skills.
- Encourage leaders to guide the group in co-defining objectives, planning actions, and fostering ownership through power shifting.
- Train leaders in maintaining clear and accurate records of meetings, decisions, and action points to support accountability and follow-up.

**2. Peer Supporter Training:**

- Train peer supporters and / or CBG leaders in Psychological First Aid (PFA).
- Equip peer supporters to provide health education on self-care practices, including skin care, wound care, exercises, and footwear use.
- Map available mental health resources and establish clear referral pathways.
- Ensure peer supporters understand and apply safeguarding principles and maintain confidentiality in all interactions.

**3. Registration of CBGs as a Civil Society Organisation:**

- Facilitate the process for CBGs to become formally registered as civil society organization to access social entitlements and participate in local advocacy.
- Engage CBG leaders actively in the registration process to promote ownership and understanding of administrative procedures.
- Use the registration process to strengthen group cohesion and reinforce accountability and governance structures.

**4. Establishment of a Local Stakeholder Panel:**

- Facilitate the process of establishing a local stakeholder panel to provide support and guidance on the relevance and quality of CBG activities, progress, and materials.
- Ensure the panel has a Terms of Reference that defines its governance functions (Appendix 8).

**5. Mapping of Linkages with Financial Sustainability Opportunities:**

- Identify potential partners and opportunities for financial support, livelihood programs, or resource access.

- Introduce these partners to CBGs and facilitate formal linkages to enable sustainable engagement.

- Encourage CBGs to plan short-term and long-term actions leveraging these linkages for group development and empowerment.

**6. End of Stage Feedback Workshop:**

- Organize a half-day workshop with CBG leaders and peer supporters to reflect on progress, challenges, and lessons learned.

- Use participatory methods to encourage open discussion, shared learning between groups, and practical problem-solving for common challenges.

- Promote ownership by inviting participants to suggest improvements, adapt activities to their context, and define next steps for Stage 2.

# Stage 2: Trust Building and Capacity Development

**Main Objective:** To consolidate trust and capacity within CBGs by strengthening autonomous self-care and psychosocial support practices and progressively transferring CBG facilitation roles to people affected.

**Stage 2 Milestones:**

| | | |
|---|---|---|
| 1 | Self-care autonomy by CBG members | ☐ |
| 2 | PSS facilitation autonomy by peer supporters | ☐ |
| 3 | Feedback mechanism in place | ☐ |
| 4 | CBG facilitation autonomy by CBG leaders | ☐ |
| 5 | CBG members access financial protection schemes | ☐ |
| 6 | Advocacy plan in place to support transition to autonomy | ☐ |
| 7 | Community engagement initiatives are identified | ☐ |
| 8 | Adequate health workforce capacity and groups are linked to a | ☐ |

**Duration:**
4 months for implementing activities. However, some CBGs may take longer in achieving milestones and be ready to transit to Stage 3

**Frequency of meetings:**
Once a month (4 visits in total)

**Target Audience:**

- CBG facilitators (NGO staff)
- CBG members
- CBG leaders
- Peer supporters
- Health workforce

# Month 4: Establishment of a Feedback Mechanism and Follow-Up

**Specific Objectives:**

- Support for all CBGs to establish a feedback mechanism.
- Tailor self-care and PSS practice to the needs of people affected, ensuring it is well understood by all CBG members.

| Core Activities | Description | Facilitator | Guiding Material |
|---|---|---|---|
| **Needs Assessment Update (15 min)** | • Review CBG purpose and needs assessment conducted in Stage 1<br>• Review ethics / code of conduct developed in Stage 1 (month 2)<br>• Update needs assessment and code of conduct as necessary | CBG leader | Appendix 1 |
| **Establishment of a Feedback Mechanism (1 hour)** | • Strengthen two-way communication between CBG members and NGO staff, ensuring community voices inform planning and proposal development<br>• Create clear channels for members to raise issues, report challenges, and hold Group leaders and peer supporters accountable<br>• Ensure CBG members are aware of safeguarding processes for serious concerns, and that these are clearly distinct from the general feedback mechanism<br>• Where appropriate, gather regular feedback to enable the CBG facilitator to evaluate member satisfaction with the model and make adjustments accordingly | NGO Facilitator with the support of CBG leader/peer supporter | Appendix 9 and 10 |
| **CBG Maintenance Session (45 min)** | • Peer supporter or Group leader to review self-care practice skills<br>• Conduct demonstrations in-person<br>• Conduct PSS as needed by peer supporter | Peer supporter with the support of an NGO facilitator | |
| **Action-Oriented Wrap-Up (5 min)** | • Review and document agreed actions, briefly clarify logistics and explain topic of next meeting | CBG leader | |

## Month 5: Training on Social Entitlements and Follow-Up

**Specific Objectives:**

- Ensure all CBGs members are trained on available social entitlements and understand the application processes.
- Ensure self-care and PSS needs are addressed through a Sustaining Core Functions session.

| Core Activities | Description | Facilitator | Guiding Material |
|---|---|---|---|
| **Presentation of Minutes (10 min)** | • Review the minutes from the previous meeting, including progress on agreed action points | CBG leader | |
| **Training in the Application for Social Entitlements (1 hour)** | • Introduce existing social entitlements/ financial support mechanisms and possible associated benefits for CBG members<br>• Discuss the importance of acquiring autonomous capacity to apply for social entitlements<br>• Assess inclusion criteria for available social entitlements within each CBG<br>• Describe the process for application step-by-step<br>• Address possible technical barriers and assign responsibilities and possible linkages based on the community asset mapping exercise conducted in Stage 1, step-4 | NGO Facilitator | |
| **Sustaining Core Functions (45 min)** | • Review self-care practice skills (include demonstrations)<br>• Conduct PSS as needed<br>• Conduct feedback session reflecting on ongoing activities | Peer supporter with the support of an NGO facilitator | |
| **Action-Oriented Wrap-Up (5 min)** | • Review and document agreed actions, briefly clarify logistics and explain topic of next meeting | CBG leader | |

# Month 6: Community Engagement and Follow-Up

**Specific Objectives:**

- Confirm all CBGs have conducted a community engagement workshop.
- Support CBG core activities — including self-care, PSS, and feedback sessions — to be self-facilitated by peer supporters and group leaders.
- Ensure self-care and PSS needs are addressed through Sustaining Core Functions session.

| Core Activities | Description | Facilitator | Guiding Material |
|---|---|---|---|
| **Presentation of Minutes (10 min)** | • Review the minutes from the previous meeting, including progress on agreed action points | CBG leader | |
| **Planning Engagement in Government or CBG-led NTD Awareness Campaign (1.5 hours)** | • Ensure that CBGs understand their role in societal impact is based on voluntary participation and should align with their purpose<br>• Use visual aids like maps, murals or calendars to illustrate concepts and make planning interactive and accessible to all CBG members | NGO Facilitator | Appendix 11, Appendix 2, 4 (reference) Community Asset Map (previously developed by the CBG) |
| **Sustaining Core Functions (45 min)** | • Review self-care practice skills (including demonstrations)<br>• Conduct PSS as needed<br>• Conduct feedback session reflecting on ongoing activities including SC, PSS and access to social entitlements | Peer supporter with the support of an NGO facilitator | |
| **Action-Oriented Wrap-Up (5 min)** | • Review and document agreed actions, briefly clarify logistics and explain topic of next meeting | CBG leader | |

# Month 7: Transition of CBG Facilitation and Advocacy Planning

**Specific Objectives:**

- Ensure all CBGs have an advocacy plan in place.
- Ensure all CBGs are self-facilitated by peer supporters and Group leaders.
- Ensure self-care and PSS needs are addressed through a Sustaining Core Functions session.

| Core Activities | Description | Facilitator | Guiding Material |
|---|---|---|---|
| **Presentation of Minutes (10 min)** | • Review the minutes from the previous meeting, including progress on agreed action points | CBG leader | |
| **Development of an Advocacy Plan (1.5 hours)** | • Assist CBGs to develop an advocacy plan, based on long-term goals identified in the needs assessment (Month 2)<br>• Discuss how NGO staff can support advocacy efforts<br>• Update Community asset mapping if necessary (Month 3) | NGO Facilitator | Appendix 12<br>Appendix 1, 4 (reference)<br>Community Asset Map (previously developed by the CBG) |
| **Sustaining Core Functions (45 min)** | • Review self-care practice skills (including demonstrations)<br>• Conduct PSS as needed<br>• Conduct feedback session reflecting on ongoing activities including self-care, PSS and access to social entitlements | Peer supporter with the support of an NGO facilitator | |
| **Action-Oriented Wrap-Up (5 min)** | • Review and document agreed actions, briefly clarify logistics and explain topic of next meeting | CBG leader | |

## Supporting Activities (Stage 2)

**1. Health Workforce Training:**

- Train healthcare providers during Stage 2 in parallel with CBG activities.
- Ensure training includes diagnosis, treatment, and basic complication management of target skin-NTDs.
- Strengthen knowledge on referral pathways to secondary and tertiary care.

**2. Document Application Procedures for Social Schemes:**

- Identify and document all relevant social entitlements available to people affected by NTDs at local, district, and state levels.
- Record clear, step-by-step procedures for accessing each entitlement, including required documents, eligibility criteria, timelines, and responsible offices.
- Assign responsibility within the CBG (e.g. leaders or peer supporters) to guide members through the application process and track progress.
- Encourage CBG leaders to maintain updated records of applications submitted, approvals, rejections, and follow-up actions.
- Support CBG members to review and update the documentation to reflect policy changes or new entitlements.

**3. End of Stage Feedback Workshop:**

- Organize a half-day workshop with CBG leaders and peer supporters to reflect on progress, challenges, and lessons learned.
- Use participatory methods to encourage open discussion, shared learning between groups, and practical problem-solving for common challenges.
- Promote ownership by inviting participants to suggest improvements, adapt activities to their context, and define next steps for Stage 3.

# Stage 3: Community Integration and Advocacy

**Main Objective:** To equip CBGs to independently lead sustainable advocacy efforts and community integration.

**Stage 3 Milestones:**

| | | |
|---|---|---|
| 1 | Networks with community and government established | ☐ |
| 2 | CBGs actively engage in community and/or advocacy initiatives | ☐ |
| 3 | CBG self-assessment conducted | ☐ |
| 4 | Sustainability roadmap agreed and in place | ☐ |

**Duration:**
5 months

**Frequency of meetings:**
Once a month (5 visits in total)

**Target Audience:**

- CBG Facilitators (NGO staff)
- CBG Members
- CBG leaders
- Peer supporters

## Month 8: Strengthening CBG Networking Capacity for Advocacy and Community Engagement

**Specific Objectives:**

- Strengthen CBG capacity to build and maintain strategic relationships with key stakeholders and networks.
- Align advocacy priorities with existing community resources.
- Identify and address gaps in stakeholder engagement and networking.
- Ensure self-care and PSS needs are addressed through a Sustaining Core Functions session.

| Core Activities | Description | Facilitator | Guiding Material |
|---|---|---|---|
| **Presentation of Minutes (10 min)** | • Review the minutes from the previous meeting, including progress on agreed action points | CBG leader | |
| **Review the Advocacy Plan and Stakeholder Map (20 min)** | • Revisit the advocacy plan and Advocacy activity tracker<br>• Review stakeholder map and identify mechanisms to engage with key stakeholders<br>• Identify remaining gaps for advocacy action | CBG leader with NGO Facilitator Guidance | Advocacy Plan and activity tracker<br><br>Stakeholder map |
| **Action planning for networking and community linkages (45 min)** | • Review seasonality calendars<br>• Discuss CBG approaches for engaging with key stakeholders adding on the seasonality calendar as needed<br>• Review and prioritize potential collaboration opportunities within local government and community initiatives<br>• Identify upcoming community meetings, events, or government discussions for participation<br>• Identify key messages, materials, logistic and timings<br>• Assign roles and responsibilities | NGO Facilitator and CBG leader | Seasonality Calendar |

| | | | |
|---|---|---|---|
| **Sustaining Core Functions (30 min)** | • Review self-care practice skills (including demonstrations)<br>• Conduct PSS as needed by peer supporters<br>• Conduct feedback session reflecting on ongoing activities Follow structure set in session-2 of Stage 2 | CBG leader and peer supporter | |
| **Action-Oriented Wrap-Up (5 min)** | • Review and document agreed actions, briefly clarify logistics and explain topic of next meeting | CBG leader | |

# Month 9: (Pathway A): CBGs will Choose to Engage in Government-led NTD Awareness Initiative (Option 1) or CBG-led NTD Awareness Initiative (Option 2)

**Specific Objectives:**

- Enable CBG participation in community initiatives through coordinated engagement with health services, local authorities, and community organisations.
- Ensure accurate community messaging and appropriate referral guidance through coordination with community health workers and programme staff.
- Ensure self-care and PSS needs are addressed through a Sustaining Core Functions session.

| Core Activities | Description | Facilitator | Guiding Material |
|---|---|---|---|
| **Presentation of Minutes (10 min)** | • CBG leader to present minutes from previous meeting | CBG leader | |
| **Community Engagement Workshop for Government or CBG-led awareness activities (1.5 hours)** | • Conduct a workshop to design an upcoming awareness campaign (This can be government-led, if a national programme is already in place, or CBG-led)<br>• Include healthcare worker orientation, CBG roles, role-play practice, and logistics finalisation | CBG Facilitator, supported by Community Healthcare Worker, CBG leader, peer supporter | Appendix 13a/b |
| **Sustaining Core Functions (30 min)** | • Review self-care skills; refresher demonstrations; assess footwear needs and referrals; PSS as needed; feedback session; conclude with NTD awareness commitments | CBG leader and peer supporter | |
| **Action-Oriented Wrap-Up (5 min)** | • Review and document agreed actions, briefly clarify logistics and explain topic of next meeting | CBG leader | |

# Month 9: (Pathway B): Preparation for Engagement in Advocacy Initiative

**Specific Objectives:**

- Review and refine advocacy issues, messages, and strategies, and update the advocacy activity tracker accordingly.
- Strengthen understanding of representation bodies, including their roles, registration process, and the benefits and opportunities that come with membership.
- Clarify how representatives are selected and establish clear communication channels for escalating advocacy issues to higher levels.

| Core Activities | Description | Facilitator | Guiding Material |
|---|---|---|---|
| **Presentation of Minutes (10 min)** | • CBG leader to present minutes from previous meeting | CBG leader | |
| **Advocacy Plan Update (45 min)** | • Review previously identified advocacy issues<br>• Refine advocacy messages<br>• Adjust advocacy strategies<br>• Update Advocacy activity tracker | CBG Facilitator, supported by Community Healthcare Worker, CBG leader, peer supporter | Advocacy Plan and activity tracker |
| **Using Representation Bodies to Advocate for Change (1 hour)** | • Provide an update on the registration process and what it involves<br>• Explain the roles and functions of different representation bodies, such as Forums, Federations, and Organisations of Persons Affected<br>• Highlight the benefits and opportunities that come with registration, including access to training, grants, and other support schemes<br>• Explain how representatives such as President, Treasurer, and Secretary are selected, and encourage members to consider getting involved<br>• Establish or clarify a clear communication channel so that advocacy issues raised by CBGs can be escalated to representation bodies for action at higher levels | CBG Facilitator | |

| | | | |
|---|---|---|---|
| **Action-Oriented Wrap-Up (5 min)** | • Review and document agreed actions, briefly clarify logistics and explain topic of next meeting | CBG leader | |

# Month 10: Acknowledge Contributions of CBGs to Community Engagement and Advocacy

**Specific Objectives:**

- Promote ownership by celebrating and acknowledging the efforts of CBGs in community engagement.
- Encourage cross learning and reflection around impact of community engagement.
- Ensure self-care and PSS needs are addressed through a Sustaining Core Functions session.

| Core Activities | Description | Facilitator | Guiding Material |
|---|---|---|---|
| **Presentation of Minutes (10 min)** | • Review the minutes from the previous meeting, including progress on agreed action points | CBG leader | |
| **Reflect and Celebrate Community Engagement Successes (30 min)** | • Feedback Session: Discuss what went well, what could be improved in terms of CBGs participation in community engagement initiatives<br>• Showcase Success stories: One or two CBG members share a brief testimonial about their participation in a recent community activity, highlighting how the experience felt, their key impressions, and any impact it had on them<br>• Certificate of acknowledgement to be presented<br>• Update CBG Seasonality calendar with next engagement | CBG Facilitator with the support of peer supporter/leader | Certificate to be provided by the government, community leader, or relevant NGO<br><br>Seasonality calendar |
| **Sustaining Core Functions (30 min)** | • Review self-care practice skills. Conduct refresher demonstrations<br>• Conduct PSS as needed by peer supporters<br>• Conduct feedback session reflecting on ongoing activities<br>• Conclude with commitments for long-term sustainability | CBG leader and peer supporter | |
| **Action-Oriented Wrap-Up (5 min)** | • Review and document agreed actions, briefly clarify logistics and explain topic of next meeting | CBG leader | |

## Month 11: Promoting CBG Ownership and Autonomy

**Specific Objectives:**

- Self-evaluate CBGs maturity and agree on roadmap for sustainability (maturity framework domains).
- Outline plan to address skill gaps through locally available resources.
- Ensure self-care and PSS needs are addressed through a Sustaining Core Functions session.

| Core Activities | Description | Facilitator | Guiding Material |
|---|---|---|---|
| **Presentation of Minutes (10 min)** | • CBG leader to present minutes from previous meeting | CBG leader | |
| **Maturity Framework Self-Evaluation (1 hour)** | • Guide CBGs through a Maturity Framework self-assessment covering key areas for independent functioning: leadership planning, skills and capacity, community linkages and resources, and minimum documentation requirements | | Appendix 14 |
| **Addressing the Gaps (30 min)** | • Community Asset mapping Update: discuss which resources available can address current gaps in group capacity<br>• Discuss which issues need to be addressed through advocacy | NGO Facilitator | Community Asset Map (previously developed by the CBG), Advocacy plan |
| **Sustaining Core Functions (30 min)** | • Review self-care practice skills. Conduct refreshing demonstrations<br>• Conduct PSS as needed by peer supporters<br>• Conduct feedback session reflecting on ongoing activities<br>• Conclude with commitments for long-term sustainability | CBG leader and peer supporter | |

# Month 12: Planning for Sustainable Phase out of NGO Support

**Specific Objectives:**

- Ensure that CBG have a clear agenda for the following 3 months.
- Ensure Sustainability plan is finalized, and follow-up actions are agreed upon.
- Ensure self-care and PSS needs are addressed through a Sustaining Core Functions session.
- Promote that CBGs take maximum ownership of their activities and maintain them autonomously, with NGO engagement reduced to quarterly oversight.

| Core Activities | Description | Facilitator | Guiding Material |
|---|---|---|---|
| **Presentation of Minutes (10 min)** | • CBG leader to present minutes from previous meeting | CBG leader | |
| **Sustainability workshop and planning (1.5 hours)** | • As CBG matures beyond self-care and PSS, CBG members must transition towards long-term financial and operational sustainability<br>• Conduct a workshop that will guide CBG facilitators and members in developing a sustainability plan that aligns with their objectives and priorities<br>• Support the CBG leader in facilitating group consensus and developing the Sustainability Plan | CBG Facilitator and CBG leader | Appendix 15 and 16 |
| **Agenda for the Next Quarter is Agreed (30 min)** | • CBG members to agree on topics for next three meetings (self-care, PSS, advocacy issues, community engagement, financial schemes etc.)<br>• Refer to Seasonality Calendar and Advocacy plan in the discussion | CBG leader | Community Asset Map (previously developed by the CBG), Advocacy plan |
| **Sustaining Core Functions (30 min)** | • Review self-care practice skills. Conduct refresher demonstrations<br>• Conduct PSS as needed by peer supporter<br>• Conduct feedback session reflecting on ongoing activities<br>• Conclude with commitments for long-term sustainability | CBG leader and peer supporter | |

## Supporting Activities (Stage 3)

**1. Cross-Learning Visits:**

- Strengthen community engagement efforts by inviting key stakeholders to meetings and events as part of ongoing relationship-building and courtesy visits.
- Facilitate peer learning exchanges by organizing learning visits for Community-Based Groups (CBGs) that have demonstrated notable success in advocacy, community engagement, or financial initiatives, enabling them to share experiences, best practices, and lessons learned with other groups.

**2. Final Dissemination Workshop:**

- Organize a dissemination event bringing together CBG leaders, peer supporters, and local stakeholders (local government officials, leaders, healthcare staff, other NGOs) to showcase the work and achievements of CBGs in the area.
- Present key advocacy priorities, challenges faced, and lessons learned, using participatory methods to encourage dialogue and shared reflection.
- Facilitate concrete action planning with stakeholders to collectively address identified challenges and strengthen ongoing collaboration.

# 4. TRAINING RESOURCES

## Basic self-care in leprosy

| | |
|---|---|
| **Skin care** | » Daily inspection for blisters, red spots, cuts and tender areas<br>» Soaking for 20 min with clean water, remove hard skin with scrubber<br>» Put any cooking oil to keep skin soft and supple<br>» Apply protective measures for daily chores |
| **Wound care** | » Skin trimming of the edges/ dressing<br>» Use local remedies when/ if available and if applicable<br>» Health seeking behaviours |
| **Exercise** | » Physiotherapy, active/passive exercise to prevent contracts<br>» Eye exercises (e.g. blinking frequently to prevent dryness 30 times/day) |
| **Footwear** | » Always wear comfortable footwear with insensible feet to prevent ulcers<br>» Quality footwear with Microcellular Rubber (MCR)<br>» Tailor made for grade-2 disability<br>» Consider foot appliances when available/ applicable |

## Basic self-care in lymphatic filariasis (lymphoedema), and podoconiosis

| | |
|---|---|
| **Skin care** | » Wash twice daily with soap and clean water at room temperature<br>» Pat-dry affected limb<br>» Daily inspection for entry points (fungal infection, ulcers, wounds) |
| **Wound care** | » Antifungal/antibacterial treatment to manage infections<br>» Health seeking behaviours |
| **Exercise** | » Massaging, active/passive exercise to reduce swelling<br>» Elevation of affected limb at night<br>» Keep moving as condition worsens |
| **Footwear** | » Always wear comfortable footwear to protect skin<br>» Tailor made for disability stage 2 or higher<br>» Insole with light weight material – Ethylene-vinyl acetate (EVA) if available |

# Basic self-care in scabies

| | |
|---|---|
| **Skin care** | » Wash affected part with soap and clean water<br>» Always keep clothing cleaned with warm water and dried in sunlight<br>» Pat dry the affected limb/ do not scratch<br>» Cut nail regularly |
| **Wound care** | » Apply lotion/ cream prescribed<br>» Comply with antibiotics prescribed, when necessary<br>» Health seeking behaviours |
| **Exercise** | » Rest (exercise should not be conducted during scabies) |
| **Footwear** | » Always wear comfortable footwear for the prevention of bacterial infections on feet |

## 4.2 Psychosocial Support (PSS)[2]

**Key Considerations:**

1. Become familiar with the definition, application, and methodology of Psychosocial Support (PSS) and Psychological First Aid (PFA).

2. Address and challenge stigmatising attitudes within the CBG and community by providing factual information on skin-NTDs and correcting misconceptions.

3. When appropriate, apply look-listen-link:

**What is look–listen–link?**

**Look**

- ✓ Check for a safe area.
- ✓ Check for people who really need help quickly.
- ✓ Check for people who are very upset or distressed.




**Listen**

- ✓ Talk nicely to people who need help.
- ✓ Ask them what they need and what is bothering them.
- ✓ Listen to people and help them to feel relaxed.
- ✓ Ask people to sit down, name things they can see around them, and encourage them to focus on their breathing.




**Link**

- ✓ Help people to go to the hospital/clinic.
- ✓ Help people cope with problems.
- ✓ Give information about where to get care.
- ✓ Connect people with family members.




4. Refer to the nearest hospital quickly if the person is very upset or wants to hurt themselves. Do not leave the person alone.

*[2] Adapted from Look Listen Link Support for Skin Sickness: Job Aid - REDRESS Implementation Manual, and Basic Psychological Support for Persons Affected by Neglected Tropical Diseases (BPS-N)*

# 5. MONITORING AND EVALUATION

## Suggested formats for collecting information to monitor the progress of CBGs:

| CBG name | Location (village) | Date of last visit | Stage 1: Foundations and governance | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|
| | | | Action plan for membership developed? (Y/N) | Governance structure documented? (Y/N) | Trained Group leader in place? (Y/N) | Local Advisory Committee established? (Y/N) | Group records being kept by CBG leader? (Y/N) | Needs assessment conducted? (Y/N) | Group purpose developed? (Y/N) | Community asset mapping completed? (Y/N) | List of financial protection schemes available within the group? (Y/N) |
| | | | | | | | | | | | |
| | | | | | | | | | | | |

| CBG name | Location (village) | Date of last visit | Stage 2: Trust building and capacity development | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | | | Members carrying out self-care regularly? (Y/N) | Meetings independently facilitated by a trained leader? (Y/N) | Peer supporter trained? (Y/N) | PSS is independently facilitated by a trained peer supporter? (Y/N) | Conducting collective feedback sessions quarterly? (Y/N) | CBG provides positive feedback to the leader? (Y/N) | CBG provides positive feedback to peer supporter? (Y/N) | Number of CBG members who access financial protection schemes | Advocacy plan documented? (Y/N) | Plan for community engagement in place? (Y/N) |
| | | | | | | | | | | | | |

| CBG name | Location (village) | Date of last visit | Stage 3: Community integration and advocacy | | | |
|---|---|---|---|---|---|---|
| | | | CBG has established contact with community and government stakeholders? (Y/N) | CBG has engaged in community and / or advocacy initiatives? (Y/N) | CBG self-assessment documented? (Y/N) | Sustainability roadmap documented? (Y/N) |
| | | | | | | |

# APPENDICIES

**Appendix 1**: Needs Assessment Template for CBG Facilitators

**Appendix 2**: Terms of Reference for the Workshop to Agree on a Common Purpose Amongst CBG Members

**Appendix 3**: Terms of Reference for the Workshop to Agree on Inclusion Criteria for New CBG members

**Appendix 4**: Terms of Reference for the Establishment of a Governance Structure for CBGs

**Appendix 5**: Terms of Reference for Identification and Selection of a Group Leader

**Appendix 6**: Terms of Reference for Identification and Selection of a Peer Supporter
**Appendix 7**: Community Asset Mapping Tool (CAMT)

**Appendix 8**: Terms of Reference for the Establishment of a Local Stakeholder Panel

**Appendix 9**: Terms of Reference to Establish Feedback Sessions within CBGs

**Appendix 10**: Terms of Reference for the Feedback Survey

**Appendix 11**: Terms of Reference for Planning Engagement and Governance in NTD Awareness Initiatives

**Appendix 12**: Terms of Reference for the Workshop on Developing an Advocacy Plan for CBGs

**Appendix 13**a/b: Terms of Reference for the Workshop on Expanding CBG Impact through Community Engagement Initiatives (Pathway A)

**Appendix 14**: Maturity Framework

**Appendix 15**: Terms of Reference for Sustainability Planning Workshop

**Appendix 16**: Sustainability Plan Template

# Appendix 1: Needs Assessment Template for CBG Facilitators

**1. OBJECTIVE**

To identify the observed and perceived health, social, and economic needs of people affected by skin-NTDs within the community, in order to inform the purpose and design of the Community-Based Group (CBG).

**2. OVERALL CBG NEEDS OBSERVED**

- Gender issues, including the need to invite care givers/ family members, footwear needs, availability of home-based SC kit resources, hygiene/nutrition, overall financial situation, emotional needs, leadership, literacy, etc.

**3. SELF-CARE PERFORMANCE**

- Degree of independency, quality SC practice, training needs.

**4. DISEASE KNOWLEDGE/ HEALTH LITERACY**

- Treatment, ability to identify complications, preventative/disease management measures, limitations, etc.

**5. HEALTH SEEKING BEHAVIOURS**

- Preferred points of care. Trust in public health facilities, knowledge on available services in public health facilities, accessibility barriers, affordability, discrimination, etc.

**6. PRIORITIZED NEEDS BY CBG MEMBERS**

- Where do CBG members want more support? Rank the overall perception from the group.

| Activity Prioritized by Members | Rank (1-low to 5-high) | Remarks |
|---|---|---|
| Information and Education | | |
| Practical SC Assistance | | |
| Support from Caregivers / Family Members | | |
| Motivation/ Encouragement | | |
| Hygiene/ Nutritional Guidance | | |
| Guidance to Apply/Availability of Social Entitlements | | |
| Access to Healthcare Services | | |
| Financial Support | | |
| Literacy/ Management Skills | | |
| Other: | | |

# Appendix 2: Terms of Reference for the Workshop to Agree on a Common Purpose Amongst CBG Members

**1. OBJECTIVE**

To define the purpose of the CBG by identifying the shared needs of its members, such as self-care, disability prevention, social support, and livelihood development, as the foundation for the group's activities.

**2. DEVELOPMENT STAGE ASSESSMENT**

- Summarise the stages described in the sustainability framework (Stage 1, 2 or 3).
- Identify the current stage of development and associated milestones according to the sustainability framework provided.

**3. INCLUSIVE PARTICIPATION**

- Encourage active participation from all members, recognising their contributions and clarifying there are no right/ wrong answers.
- Start with a reflection about the members decision to join the group in the first instance, but recognising the needs raised during the need's assessment.
- Reflect on future needs around advocacy and community integration activities (Stage 3).
- Create regular feedback spaces where members express their thoughts on the process.

**4. BRAINSTORMING**

- Initiate brainstorming discussions by collectively identifying themes related to each development stage and their impact on the CBG development in the mid and long run. Document these themes.
- Draft a preliminary purpose statement based on the themes documented and identified by the group members.
- Discuss how the needs identified in the need´s assessment process fit with each theme.
- Adjust purpose statement based on the feedback and ensure alignment with the CBG current developmental stage (i.e. Stage 1).
- Allow for a final round of discussion and adjustments if necessary.
- Draft and document the final purpose statement.
- Acknowledge the collective effort of all CBG members in defining the group´s purpose.

**5. RECORD KEEPING**

- Develop minutes of the workshop, ensuring that the process reflects the group´s participation.

# Appendix 3: Terms of Reference for the Workshop to Agree on Inclusion Criteria for New CBG Members

**1. OBJECTIVE**

To collectively define inclusion criteria for new CBG members - covering eligible conditions, age thresholds, and participation arrangements for family members and caregivers- while developing an action plan for welcoming new members and a process for documenting and reviewing these decisions.

**2. INCLUSION CRITERIA**

- Encourage members to be open and accepting other people with diverse health conditions that could benefit from the group´s activities.
- Challenge any stigmatising attitudes by providing accurate information on different skin-NTDs, debunking related myths and misconceptions, and explaining their negative effects.[1]
- Offer examples of diseases or conditions that could fit in the group, previously assessing its suitability and operational feasibility for the NGO facilitating the group under Stage 1 according to the sustainability framework described in the CBG manual (e.g. other chronic disabilities, other skin-NTDs, extreme poverty, etc.).
- Age thresholds may need to be established for children and the elderly, considering their support needs and possible commitment challenges.
- Sporadic or continuous participation, as well as active membership need to be considered for family members and care givers, based on the specific needs of old/new CBG members, migration, etc.
- Consider the involvement of other community stakeholders, such as healthcare providers and community leaders, possibly contributing to a more holistic support system.
- Draft and document the final inclusion criteria.
- Acknowledge the collective effort of all CBG members in defining the group´s inclusion criteria for new members.

**3. ACTION PLAN DEVELOPMENT**

- Plan for mainstreaming decisions taken, considering welcoming and orientation and the need´s assessment that must be conducted for new members.
- Identify group members who will support and guide new members in their initial integration.

**4. RECORD KEEPING**

- Develop minutes of the workshop, ensuring that the process reflects the group´s participation.
- Establish a mechanism for ongoing feedback on how the inclusion criteria aligns with the evolving stage, themes and emerging needs of CBG members.

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*[1] Source: Look Listen Link Support for Skin Sickness: Job Aid - REDRESS Implementation Manual*

# Appendix 4: Terms of Reference for the Establishment of a Governance Structure for CBGs

## 1. OBJECTIVE

To establish an initial governance structure CBGs, as a framework for effective leadership, functionality, coordination, and decision-making within CBGs.

## 2. GOVERNANCE STRUCTURE COMPONENTS

- Agreed Group size (range):
  - *Include seasonality considerations that may affect meeting frequency.*

- Roles and responsibilities:
  - *Group leaders identified following Terms of Reference in **Appendix 6?** YES/NO. If NO, please comment on proposed modifications.*

  - *Peer supporter identified following Terms of Reference in **Appendix 7?** YES/NO. If NO, please comment on proposed modifications.*

- Describe agreements around the role of family members/ care givers.
- Needs assessment:
  - *Agree frequency of needs assessments to ensure ongoing relevance and responsiveness to the evolving needs of CBG members.*

## 3. EVALUATION AND ADAPTATION

- Describe any plans set for periodic evaluation, with adjustments made, if necessary, based on feedback and CBG stage needs.

# Appendix 5: Terms of Reference for Identification and Selection of a Group Leader

**1. OBJECTIVE**

To identify a committed and capable group leader who can effectively lead, coordinate, and sustain CBG activities on a regular basis, ensuring the group remains organised, motivated, and responsive to members' needs.

**2. EXPLAIN ROLES AND RESPONSIBILITIES** (See section 2.3 Facilitation as a Phased Handover)

**3. ELIGIBILITY CRITERIA**

- The group leader must be a CBG member.
- Active member in group activities (motivation, commitment).
- Leaders should ideally have basic literacy skills to support communication, documentation and training participation; where this isn't possible, candidates who can be supported by a caregiver for written communication may be considered.

**4. SELECTION PROCESS**

- During this step, group members will vote for potential candidates that meet the inclusion criteria for the group leader role.
- The individual with more votes will be selected as a Group leader.
- In the nomination process, highlight that the selection of a group leader is based on group consensus to ensure collective decision-making.

**5. DURATION**

- The role of group leader will be appointed for at least 12 months or when the group transits to Stage-3, if necessary, allowing regular rotation to encourage shared leadership and fresh perspectives.

**6. SUPPORT AND TRAINING**

- Arrange for an orientation session for the selected group leader so he/she understands the role, responsibilities and available support.
- Provide continuous training and capacity-building opportunities to strengthen his/her leadership skills (e.g. management skills, accountability skills, financial skills, specific leadership skills, etc.).

**7. ACCOUNTABILITY AND REPORTING**

- Specify the reporting mechanisms for the group leader to regularly update the group on activities, challenges and achievements.
- Make sure the group leader meets with NGO coordinators, so agenda items are up to date.
- Establish a feedback mechanism for CBG members to provide input on the group leader’s performance.

**8. GENDER CONSIDERATIONS**

- Encourage nominations and selection processes that promote gender balance within leadership roles.

**9. REMOVAL PROCESS**

- Agree with CBG members clear grounds for the potential removal of the group leader (e.g. persistent non-compliance with responsibilities, unethical practice, etc.).
- Agree with CBG members the procedure for the removal of the leader, ensuring fairness and transparency.

# Appendix 6: Terms of Reference for Identification and Selection of a Peer Supporter

**1. OBJECTIVE**

To identify and select a qualified and empathetic individual with lived experience of mental health conditions and/or psychosocial disabilities that can act as peer supporter, facilitating basic psychosocial support to other CBG members.

**2. EXPLAIN ROLES AND RESPONSIBILITIES** (See section 2.3 Facilitation as a Phased Handover)

**3. ELIGIBILITY CRITERIA**

- The peer supporter must be a CBG member, ideally different than the group leader.
- Active member in group activities (committed, motivated).
- ·Ideally an individual with lived experiences of mental health conditions and/or psychosocial disabilities.
- Ideally, should have basic literacy skills (read and write) to ensure effective communication, documentation and participation in training activities.
- Must have good communication skills.

**4. SELECTION PROCESS**

- NGO staff typically identify this role after observing group dynamics, though it may instead be nominated in a voting system similar to the group leader's (See Appendix 5).
- This role should be identified in Stage 1 and trained at the beginning of Stage 2.

**5. DURATION**

- The role of peer supporter will be at least appointed until the group reaches developmental Stage 3 and longer if necessary.

**6. SUPPORT AND TRAINING**

- Arrange for an orientation session for the selected peer supporter so he/she understands the role, responsibilities and available support.
- Provide continuous training and capacity-building opportunities to strengthen his/her psychosocial support skills:

    - Use of basic psychosocial support tool for NTDs (BPS-N/PFA)
    - Identify when people need prompt referral to specialised mental health support
    - Communication with family members
    - Analytical skills
    - Self-care practice
    - Facilitation skills

**7. ACCOUNTABILITY AND REPORTING**

- Specify the reporting mechanisms for the peer supporter in collaboration with NGO coordinator.
- Establish a feedback mechanism for CBG members to provide input on the peer supporter's performance.

**8. GENDER CONSIDERATIONS**

- Encourage nominations and selection processes that promote gender balance within leadership roles.

**9. REMOVAL PROCESS**

- Agree with CBG members clear grounds for the potential removal of the peer supporter (e.g. persistent non-compliance with responsibilities, unethical practice, insufficient skills, etc.).
- Agree with CBG members the procedure for the removal of the peer supporter, ensuring fairness and transparency.

# Appendix 7: Community Asset Mapping Tool (CAMT)

**1. OBJECTIVE**

Support the CBG to identify existing assets within their surroundings that can address the group's health, psychosocial, or economic needs, thereby strengthening its network and long-term sustainability.

**2. SELECT MAPPING METHOD**

- Listing
- Drawing
- Others: Community Walk, Digital

**3. COMMUNITY ASSETS IDENTIFICATION**

- Individuals (include name, gender, contact information)
    - o Health workers
    - o Health volunteers
    - o Counsellors
    - o Community leaders
    - o Religious leaders
    - o Traditional healers
    - o Teachers (literacy)
    - o Local experts in cross-cutting issues (health, water and sanitation, agriculture, etc.)
    - o Others
- Associations (include contact information)
    - o Other Community groups (associations of people affected, etc.)
    - o Self-support groups
    - o Community health governance committees
    - o Youth organizations
    - o Women´s groups
    - o Religious groups
    - o Sports and physical activities groups
    - o Psychosocial / mental health support associations
    - o Agricultural/ farmer groups
    - o Others
- Institutions (include contact information)
    - o Local government (Panchayati Raj Institutes/ Union Parishads/Woreda...)
    - o Health facilities (name, location, services offered, health workforce, etc.)
    - o Mental health services (location, private/public services, specialists, etc.)
    - o Educational institutions (school segmentation)
    - o Literacy-focused Institutions
    - o Religious institutions (temples, mosques, churches, etc.)
    - o Environmental Protection Organizations
    - o Microfinance institutions
    - o Other local or international NGOs
    - o Others

- Physical Spaces
    - o Community gathering spaces
    - o Outdoor spaces (parks, gardens, squares)
    - o Local government meeting spaces
    - o Private spaces (courtyards, homes)
    - o Agricultural land, crops
    - o Abandoned land, houses
    - o Others
- Economic/Exchange (include contact information)
    - o Skill development programs (incl literacy)
    - o Adult education groups
    - o Hobbies and Social clubs
    - o Advocacy initiatives (community-led, NGO-led, ...)
    - o Professional associations
    - o Private companies
    - o Farming opportunities (types of crops, livestock, etc.)
    - o Income generating activities (IGA)
    - -Possible opportunities (small-scale businesses, etc.)
    - -Training programs (entrepreneurship, financial/ management literacy, etc.)
    - o Others
- Cultural/Historical (include contact information)
    - o Cultural Organizations
    - o Libraries
    - o Community Events and Festivals
    - o Media Organizations
    - o Performing Arts Organizations
    - o Other

**4. POTENTIAL FOR INVOLVEMENT OF CBGS IN ACTIVITIES**

- Specific NTD awareness campaigns (dates, details, etc.).
- LF related MDA campaigns (dates).
- Active case finding activities (dates, methods, etc.).
- Other programs (NTD, WASH related, One-health, etc.).

**5. RECOMMENDATIONS AND NEXT STEPS**

- Ranking of assets

oList assets that are already working well in the community.
oList assets that exist but that need improvement (have structural issues, not enough information about, issues with opening hours).
oList non-existent assets that CBG members must leave the community to get access to.

- Define Short-term actions
- Define Mid-term networking actions

# Appendix 8: Terms of Reference for the Establishment of a Local Stakeholder Panel

**OBJECTIVE**

A local stakeholder panel aims to support and guide in the coherence and appropriateness of ongoing activities, progress and/or materials developed for community-based groups (CBGs).

**1. COMPOSITION**

- Composition must include representation from CBGs and local stakeholders with experience with CBG work.
- At least X% of members (Y% women) must be people affected by leprosy or other skin-NTDs who are members of UPLIFT CBGs.

**2. ROLES AND RESPONSIBILITIES**

- Provide feedback to CBG progress reports shared.
- Provide feedback on issues, advocacy aspects, challenges and concerns raised in monthly CBG meetings.
- Providing feedback on ongoing activities.
- Commit to membership in Local Stakeholder Panel for at least 24 months. Review training materials upon request.
- Support in the interpretation of findings.

**3. EXPECTATIONS**

- Confidentiality with the panel's feedback must be maintained.
- Active participation is expected in planned meetings and upon request when panel members are requested to input on specific issues.
- Regular attendance to scheduled meetings.

**4. MEETING FREQUENCY**

- The local stakeholder panel members must meet at least once quarterly.

# Appendix 9: Terms of Reference to Establish Feedback Sessions within CBGs

**OBJECTIVE**

To establish a feedback mechanism that enables CBG members to regularly share input on group activities, needs, and challenges, ensuring the group remains responsive, participatory, and continuously improving.

**1. INTRODUCTION AND GROUND RULES**

- Introduce the scope of the feedback session: CBG ongoing activities, public health services, exposure to community activities, including case detection activities and any other NGO relevant work beyond UPLIFT.
- Revise last needs assessment and community asset mapping done by the group
- Comment that everyone is invited to share their personal opinion and every opinion will be fully respected and listened to.
- Clarify that what is shared in the feedback session stays within the group.
- Encourage CBG members to share their thoughts constructively.

**2. AGENDA**

1. Icebreaker (5 min)

- Share one positive experience from the CBG.

2. Reflection on previous feedback points (if second meeting onwards)

- Reflect on the actions taken in previous feedback sessions and explore if anything needs further attention.

3. Reflection on ongoing activities (15 min)

- Discuss current activities
- Ask what has been more beneficial to members.
- Ask if the activities could be improved.
- Ask if the group is going in the right direction, considering the needs assessed, community assets mapped, the group´s purpose and the milestones established for each stage.

4. Reflection on external activities

- Discuss exposure to NTD programme activities in the wider community such as case detection, MDA campaigns, vector control, etc.
- Discuss exposure to public health services, including access and availability.

5. Leadership and peer supporter roles (10 min)

- Ask to provide feedback on the facilitation skills of both the group leader and peer supporter.
- Ask to provide feedback on their performance.

6. New ideas and suggestions (15 min)

- Facilitate brainstorming of possible new ideas, activities or solutions to raised issues.

7.Addressing concerns/ challenges (15 min)

- Immediate actions required
  - Actions to be taken by CBGs
  - Support required by NGO staff

- Mid-term/long-term actions required
  - Programmatic changes suggested
  - Training needs
  - Others

- Follow-up and responsibilities
  - Assigned responsibilities
  - Timeline for follow-up

**3. RECORD KEEPING**

- Assist note taker in developing minutes of the session, ensuring that the process reflects the group´s participation.

**4. REPORTING**

- NGO staff to report on the general feedback session using given template below.
- Reporting frequency: quarterly.

*Confidentiality Note: All sensitive information provided in this report will be handled with strict confidentiality as required and appropriate, in alignment with existing safeguarding policies.*

# Appendix 10: Terms of Reference for the Feedback Survey

**OBJECTIVE**

This feedback survey is designed to guide the CBG external facilitator in assessing member satisfaction with CBG activities and leadership, while gathering constructive feedback to inform adaptations where necessary.

**1. ACTIVITY FEEDBACK**

a) How satisfied are you with the current ongoing activities within the group overall?

- o Very satisfied
- o Satisfied
- o Neutral
- o Dissatisfied
- o Very dissatisfied

b) Please select the activities you have undertaken within the group for the last 6 months.

- o Self-care
- o Psychosocial support
- o Participation in community activities
- o Participation in advocacy events
- o Income generating activities /livelihoods
- o Skill development training
- o Other: _____

  i. What challenges, concerns or new ideas would you like to share to improve current or future activities?

**2. FACILITATION FEEDBACK**

a) How satisfied are you with the performance of the group leader?

- o Very satisfied
- o Satisfied
- o Neutral
- o Dissatisfied
- o Very dissatisfied

b) Please provide feedback or suggestions for improving the role of the group leader.

c) How satisfied are you with the performance of the peer supporter?

- o Very satisfied
- o Satisfied
- o Neutral
- o Dissatisfied
- o Very dissatisfied

d) Please provide feedback or suggestions for improving the role of peer supporter.

# Appendix 11: Terms of Reference for Planning Engagement and Governance in NTD Awareness Initiatives

**OBJECTIVE**

This workshop is designed to empower CBG members to leverage their just acquired skills and knowledge to contribute meaningfully to broader societal impact. CBGs will explore opportunities for engaging in community health initiatives and build networks with key stakeholders. This process underscores that the role of CBGs in societal improvement is legitimate and of collective responsibility.

**WORKSHOP OUTLINE**

**1. Welcome and introduction**

- Introduce the concept of societal impact and legitimacy in establishing CBGs as trusted community stakeholders.
- Bring the CBG's purpose (Stage-1) to ensure alignment. Update purpose if necessary (Appendix 2).
- Introduce the potential impact that CBGs can make in the wider community through engagement in local initiatives.

**2. Overview of current community and NTD programmes**

- List ongoing health initiatives in the community, including NTD-related activities, vector-control, community awareness, WASH and other community-focused efforts.
- Discuss on how CBGs can align with or enhance these programs.

**3. Stakeholders/partnership mapping**

- Identify key stakeholders to approach for partnerships/networking that are related to the activities listed above. Consider existing Network for persons affected by NTDs, and/ or persons with disabilities, and explore opportunities to collaborate.
- Participatory exercise 2: Update the Community asset mapping discussed under Stage-1 (Appendix 7). Assist CBGs in creating a tailor-made map listing potential partners, health facilities, village-level health/sanitation committees, government officials and other community organizations.

**4. Brainstorming on engagement opportunities**

- Brainstorm ways for CBG members to engage in existing NTD-related campaigns, local governance and other community development activities. For this, assist CBGs to develop a seasonal calendar, allocating environmental aspects and the best timings for possible engagement.
- Develop "Seasonal calendar planning" (see Figure-1 below)

*- CBG members brainstorm using paper and/or mural on existing community health activities.*
*- CBG members place these activities on a seasonal calendar to visualize seasonal events and context, existing activities (e.g. Community awareness, case detection campaigns, vector-borne disease control activities, etc.).*

CBG members discuss on the best timing for engagement, aligning with environmental factors for the most effective engagement.

**5. Develop an Action Plan**

- Assist CBG members in drafting a flexible action plan with key roles and timelines, allowing each CBG to personalise its plan according to interest, availability and resources.

**Note: Not all members may be interested or willing to engage with the same activities which is fine.**

**6. Document**

- Assist CBG leaders documenting the actions, timings and roles agreed

*Figure-1: Example of seasonal calendar for Bihar, India*

| **SEASON** | **Example: Winter (Shita Ritu) Dec- Jan** | | | |
|---|---|---|---|---|
| **Major Festivals** | Harvest, religious | | | |
| **Agriculture** | *Rabi seeding (Dec-Jan)* | | | |
| **Other facts/behaviors (economic, hygiene, ceremonies, migration, holidays, weather)** | *Peaks of poverty*<br>*Long PHC waiting lists/ Busy Out-patient services (peaks of cough, asthma, cold)* | | | |
| **NTD related facts (incidence of complications, challenges in reach or coverage, mental health status)** | *Low ACF reach/coverage*<br>*LF Acute attacks (Nov-Jan)*<br>*Depression* | | | |
| **NTD activity** | World Leprosy Day – campaign on mental health and NTDs | | | |
| **Stakeholder (responsible for the role out of NTD activity)** | *PHC staff* | | | |
| **Resources needed** | *Printed awareness activities* | | | |
| **CBG members interested** | *Name/surname* | | | |

# Appendix 12: Terms of Reference for the Workshop on Developing an Advocacy Plan for CBGs

**OBJECTIVE**

This workshop aims to guide CBGs in the development of a collective advocacy plan, equipping them with the skills to identify and address key issues affecting their communities. By updating their purpose, assessing the situation and identifying key stakeholders, CBGs will be able to formulate an advocacy plan to effectively communicate their needs and rights, enhancing their overall impact for people affected by skin-NTDs.

**WORKSHOP OUTLINE**

**1. Welcome and introduction**

- Introduce the concept of advocacy and its importance in driving long-term community change.
- Introduce the potential impact that CBGs can make in the wider community through effective advocacy activities and as registered CBGs.

**2. Set Advocacy goals**

- Review the CBG's purpose and needs assessment (Stage 1, step-2,3) to identify CBG priorities for advocacy.
- Assist CBG members in listing broad, long-term goals for advocacy (later narrowing these down into more focused objectives).

**3. Situational analysis**

- Present an overview of existing policies, social entitlements and ongoing programs affecting skin-NTDs, highlighting challenges and access barriers.
- Identify areas and opportunities where CBGs can participate in advocacy work.
- Identify key local stakeholders, organizations, community leaders to support CBGs in advocacy work.
- Discuss CBG strengths and weaknesses to engage with advocacy activities. Identify training needs and support required.
- Explain how CBG registration can help in advocacy activities. Revise the current situation with respect to CBG registration at district/state level and prioritise necessary actions for completing this task.

**4. Action plan**

- Assist CBG members defining specific, feasible objectives for the CBG advocacy work that address CBG needs.
- Adjust CBG purpose and needs assessment if necessary (Appendix 1 and 2).
- Assist CBG members in drafting a flexible action plan with specific key activities, messages, roles and timelines, allowing each CBG to personalise its plan according to interest, availability and resources.
- Develop a plan for networking and partnering with key stakeholders identified.
- Reiterate the voluntary nature of all engagements, emphasizing that each CBG defines the scope of its involvement.

Note: Not all members may be interested or willing to engage with advocacy work which is fine.

**5. Monitoring**

- Identify mechanisms for monitoring and follow-up.

**6. Document**

- Assist CBG leaders documenting the actions, timings and roles agreed.

**Example of an Advocacy activity tracker:**

Fill in this advocacy tracker tool at the start of an advocacy initiative – and when you have small or intermediate wins.

| **Goal:** | | | | | |
|---|---|---|---|---|---|
| **Brief description of activity** | **Intermediate win it contributes to** | **Date of activity** | **Advocacy target (agency, person)** | **Result and/or Follow-up actions** | **Brief reflection on the effectiveness of the activity** |
| | | | | | |
| | | | | | |
| | | | | | |

# Appendix 13a: Terms of reference for the workshop on expanding CBG impact through Community Engagement initiatives – Government led Activities (Pathway A)

**OBJECTIVE**

To co-design, in partnership with government stakeholders, a community engagement initiative that enables CBGs to actively contribute to societal impact and stronger integration with local systems and services.

**1. Welcoming Community Healthcare worker (20 min):**

- Healthcare worker to explain importance of NTD initiatives and government plans for awareness activities.
- Clearly identify roles and responsibilities, including entry points for CBGs into government-led initiatives.

**2. Role of CBGs in NTD awareness (30 min):**

- What influences communities' behaviours around NTDs? (in depth discussion, including cultural beliefs etc.).
- How can CBGs increase awareness/change behaviours around the specific NTD?
- Select members who can share testimonials to increase awareness*

**Involve the peer supporter and be mindful when discussing sensitive topics. Use Psychological First Aid (PFA) principles if needed.*

**3. Awareness role-play (30 min):**

- Practice how of each CBG member and Community healthcare worker interacts during the campaign (roles, responsibilities).
- Practice testimonials that can support during awareness campaign.
- Introduce IEC materials (banners, pamphlets) and practice how to use them.

**4. Finalizing logistics (10 min):**

- Exchange contact details of CBG leaders, agree on date, meeting place and IEC distribution plan.
- Review self-care practice skills. Conduct refresher demonstrations, assess need for footwear, referrals.
- Conduct PSS as needed by peer supporters.
- Conduct feedback session reflecting on ongoing activities.
- Conclude with commitments for participating in NTD awareness.

Review and document agreed actions and briefly clarify logistics and explain topic of next meeting.

# Appendix 13b: Terms of reference for the workshop on expanding CBG impact through Community Engagement initiatives – Government led Activities (Pathway A)

**OBJECTIVE**

To co-design, in partnership with government stakeholders, a community engagement initiative that enables CBGs to actively contribute to societal impact and stronger integration with local systems and services.

**1. Welcome and Introduction (10 min):**

1. Brief overview of the awareness raising topic (e.g. leprosy screening or contact tracing, MDA for LF, Hygiene for scabies prevention, stigma reduction, integrated Skin NTDs etc.).
2. Ground rules for the workshop (respect, safe space, maintain privacy).

**2. Barrier Mapping (30min):** Participants share lived experiences:

- How did you first learn you had an NTD? *
- How did people around you behave? What helped you? What made it harder? *
- What makes people avoid prevention efforts (screening, drugs) or seeking treatment? (in depth discussion, including cultural beliefs etc.).

**Involve the peer supporter and be mindful when discussing sensitive topics. Use Psychological First Aid (PFA) principles if needed.*

**3. Message Brainstorm (20min):** What Should People Know?

- What messages could help overcome the barriers we talked about? (consider messages beyond the biological/medical aspects of NTDs).
- Everyone shares: “One message I want people in the community to hear is...”
- As a group, agree on one key message and write it down in your notebook for the CGB.
  - Our group message is _____.”

**4. Choose a channel (20 min):** What communication methods work in their communities?

- Discuss pro-cons for each channel: Social media? Posters? Leaflets? Banner? Others (new ideas)
- What spaces feel safe or trusted to conduct the campaign?
- Agree on one channel and one location per CBG.

**5. Choose a messenger (15 min):** Who should deliver the message?

- List names of group participants willing to participate.
- Discuss who else should be invited: Community health workers, local authorities, School teachers, religious leaders, others.
- Make a concrete plan to engage with other stakeholders (who, when, where).

**6. Draft rough concept (20 min) (poster, banner, short play, radio script, etc.)**

- Discuss how their ideas will inform the official campaign.
- Offer opportunities to CBG members to stay engaged as champions.

**7. Wrap-Up:**

- Review and document agreed actions and briefly clarify logistics and next steps before the campaign.

# Appendix 14: Maturity Framework

## OBJECTIVE

The maturity framework is a tool designed to help CBGs assess their level of maturity across five key domains. It supports preparation for phase-out and serves as a foundation for the subsequent Sustainability Planning session. It can be reviewed periodically by CBGs or NGO facilitators to track progress towards maturity and enhance sustainability efforts.

## INSTRUCTIONS

For each domain, consider the key monitoring questions. Then identify strategies, indicators and frequency of evaluation for each. This form can be used quarterly to track progress towards CBG autonomy.

| Domain | Key Monitoring Questions | Suggested Strategies (Answers) | Example Indicators | Evaluation Frequency |
|---|---|---|---|---|
| **1. Leadership and Ownership** | Who will be supporting the groups once the project ends? | | % of groups with trained Leaders<br>% of groups conducting meetings with minimum NGO facilitation<br>% of groups supported by healthcare personnel or non-healthcare personnel | Quarterly |
| **2. Capacity / Skills** | Which skills are fundamental for sustainable CBGs? | | % of Leaders trained in “refresher” (leadership, recordkeeping, advocacy)<br>% of peer supporters able to facilitate sessions selfcare sessions independently<br>% of leaders demonstrating ability to facilitate sessions independently | Quarterly |

| | | | | |
|---|---|---|---|---|
| **3. Resources and Links** | How will links to assets/resources be maintained?<br><br>How will financial sustainability be ensured? | | % of groups with community health workers regularly attending meetings<br>% of groups with 1 member attending local decision-making forums<br># of groups with active linkages to government schemes or livelihood programme<br>% of groups maintaining financial records (savings, loans)<br># groups registered as Corporate Societies<br>% of groups with an advocacy plan in place<br>% of groups with established links to State-level Forum (Chairperson)<br># of Advocacy meetings attended by Forum Chairperson | Quarterly |
| **4. Community Engagement** | How will visibility and engagement in community activities be maintained? | | % of groups with 1 member attending local decision-making forums<br>% of groups participating in NTD awareness events<br>% of groups participating in local advocacy initiatives | Quarterly |
| **5. Learning, Accountability & Documentation** | What is the minimal documentation / monitoring needed to ensure progress is tracked? | | % of groups maintaining key documents (membership list, meeting minutes, advocacy plan, +/-financial logs) | Quarterly |

# Appendix 15: Terms of Reference for Sustainability Planning Workshop

**OBJECTIVE**

To ensure the long-term sustainability of CBGs by strengthening financial self-reliance, advocacy, community participation, and governance structures, in line with the group's own priorities and capacities.

**1. METHODS**

Step-1: Introduction and purpose

- Explain the workshop purpose
- Revise CBG´s long term objectives from stage-1 to ensure sustainability efforts align with the objectives and needs of the group. Assist members if objectives/needs require adjustment

Step-2: Financial sustainability

- Assist and brainstorm to identify potential IGA that align with CBG skills, local market needs and CBG objectives.
- Review “Resources and links” (Appendix 7) developed during stage-1 to ensure IGAs match previously identified opportunities.
- Explore IGAs based on CBG skills, local market demands and available technical support from community or government stakeholders. Explore necessary linkages to be conducted.
- Identify any other possible funding sources.
- Explore willingness of CBG members to contribute through savings or connect with existing savings/loan groups in the community.
- Ensure capacity and access to social entitlements.
- Discuss the necessary technical support required for developing a business plan, including capacity, conflict resolution guidance, basic accounting skills, etc.

Step-3: Advocacy

- Explore CBGs' initial motivation for forming a higher-level representation network that provides access to national or regional platforms, including options for incorporating groups into existing national/regional networks. Ensure all members understand both the benefits of this (increased recognition, accelerate advocacy initiatives, etc.) and the challenges (e.g. fees, bureaucracy, potential financial monitoring) involved, and discuss potential obstacles and solutions for successful implementation at both regional and local levels.
- Revise key advocacy actions and re-define steps for engaging local authorities/ key stakeholders as needed.
- Adapt existing advocacy objectives (Appendix 12) to match evolving CBG needs and capacity.

Step-4: Community participation

- Revise available NTD-related activities (Appendix 11) and re-define how CBGs will engage in these programmes to maintain visibility and impact in the wider society (Appendix 13). Schedule specific actions for the next 6-12 months.

Step-5: Governance

- Revise the governance structure, ethics, inclusion criteria and roles discussed during Stage 1. Re-define roles and responsibilities as necessary, including leadership rotations.
- Ensure CBG members understand that from now onwards, the facilitation role sits on CBG leaders and peer supporters, although (depending on context and resources) NGO facilitators may still support technically in some instances.

**2. DRAFT SUSTAINABILITY PLAN**

- Note taker (or any other designated member) summarises key workshop outcomes.
- CBG members complete the sustainability plan template (Appendix 16).
- The CBG leader will review and refine the sustainability plan during the next few monthly visits (now without the entire support of NGO facilitators).

# Appendix 16: Sustainability Plan Template

**OBJECTIVE**
This template documents the outputs of the sustainability workshop (Appendix 15) and incorporates them into an actionable CBG-owned plan.

**1. FINANCIAL SUSTAINABILITY PLAN**

- Income generating activities (IGA)

| | |
|---|---|
| IGAs identified that align with CBG skills | 1.<br>2. |
| Resources needed to start IGAs | 1.<br>2. |
| Relevant stakeholders, infrastructure and resources identified that could support the implementation of IGAs | 1.<br>2. |
| Roles and responsibilities within the group | 1.<br>2. |
| Initial steps for IGA implementation | 1.<br>2. |

- Additional funding support

| | |
|---|---|
| Potential funding sources (government support, livelihood support programs, social entitlements, partnerships, etc.) | 1.<br>2. |
| Community resources (savings groups, local partnerships...) | 1.<br>2. |
| CBG possible contributions (pooled savings, shared resources, member fees, etc....) | 1.<br>2. |
| Roles and responsibilities within the group | 1.<br>2. |
| Technical support required, including skill building | 1.<br>2. |
| Initial steps to access funding | 1.<br>2. |

## 2. ADVOCACY

| | |
|---|---|
| Steps for CBG registration at regional/local levels | 1.<br>2. |
| Responsibilities within the group for overseeing registration | 1.<br>2. |
| Key advocacy priorities for the next 6-12 months | 1.<br>2. |
| Stakeholders that need to be engaged (government, NGOs, community leaders, healthcare providers, etc.) | 1.<br>2. |
| Technical support required, including skill building | 1.<br>2. |
| Initial steps for advocacy action | 1.<br>2. |

## 3. COMMUNITY ENGAGEMENT

| | |
|---|---|
| NTD programmes or community initiatives that CBGs will engage in | 1.<br>2. |
| Plan to participate in local health and development initiatives (WASH, MDA, case detection, community awareness, vector control, etc.) | 1.<br>2. |
| Roles and responsibilities within the group | 1.<br>2. |
| Technical support required, including skill building | 1.<br>2. |
| Initial steps for community engagement activities | 1.<br>2. |

## 4. GOVERNANCE

| | |
|---|---|
| Current leadership roles within the CBG | 1.<br>2. |
| New roles looking ahead (treasurer, advocacy lead, IGA coordinator, community champion, etc.) | 1.<br>2. |
| Plan for leadership rotation | 1.<br>2. |
| Others | 1.<br>2. |

## 5. NEXT STEPS

| | |
|---|---|
| Immediate next steps | 1.<br>2. |
| Key roles and responsibilities | 1.<br>2. |
| Immediate technical support required | 1.<br>2. |

**Signatures of CBG Leaders:**

### Feedback survey

Please use the QR code to provide your feedback on the Facilitation Guide for Community Based Groups:

UPLIFT Facilitation Guide Feedback Survey

Facilitation Guide for Community-Based Groups