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# Community-based models for neglected tropical diseases affecting the skin: a scoping review

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Skin neglected tropical diseases (NTDs) cause physical impairments, and socioeconomic and mental health impacts, often exacerbated by social stigma. The WHO 2030 road map calls for integrated, person-centred care; community-based groups (CBGs) present a community-led solution. However, evidence is limited and CBGs are not consistently being operationalised across health systems. The UPLIFT study is developing and piloting a harmonised CBG tool. This scoping review aimed to identify preferred practices in existing skin-NTD CBG models and recommend a holistic framework for best practice. We searched four peer-reviewed databases and key organisations' websites, for terms related to CBGs and skin-NTDs. Eligible studies explored community models and skin NTDs and were published in English from 2000 onwards. Studies with quantitative, qualitative, or mixed method approaches, and secondary analysis or evidence synthesis were eligible. Studies failing to fulfil the criteria, opinion pieces, cross-sectional surveys, editorials, and case studies were excluded. Outcomes on key CBG domains were thematically identified and explored from literature and discussions with subject matter experts: self-care, mental health, livelihood, and governance. Data were compiled in Excel and charted according to CBG domain and other key information (e.g., outcome and method of measurement), before writing up findings thematically. Fifty-four eligible citations were identified, including 38 peer-reviewed papers. Most studies were pretest/posttests conducted in Asia, targeting mainly leprosy, with heterogeneity in study designs and evaluative measures. Only four studies explored all CBG domains, with few CBGs including formal mental health support, livelihood activities and advocacy and awareness activities. Current research on the burden of skin-NTDs is predominantly focused on leprosy, leaving a significant gap in research on other skin-NTDs, particularly in the

African region. Most CBGs are failing to integrate into health systems and mainstream important programmatic components such as sustainability and gender considerations. To address these gaps and work towards a harmonised CBG approach, we present a framework of best practice and recommend further research, targeting multiple skin-NTDs in unison.

#### KEYWORDS

skin neglected tropical disease(s), peer support, self-care, mental health, equity, person-centred health system, sustainability, gender

## 1 Introduction

Neglected tropical diseases (NTDs) impact nearly 1.7 billion people globally, prevailing in the most marginalised communities and perpetuating poverty and inequality (1). Skin NTDs are a subset of NTDs which impact the skin and subcutaneous tissues and include leprosy (Hansen's Disease), Buruli ulcer (BU), lymphatic filariasis (LF), onchocerciasis, scabies, podoconiosis, yaws and cutaneous leishmaniasis (CL) (2). Skin NTDs are among the top 10 causes of disability and the third most common cause of illness globally (3). Whilst manifestations and treatments vary, skin-NTDs are unified in causing severe long-term consequences, including irreversible physical impairment, socio-economic impacts, mental distress and social stigma (3).

The WHO NTD Road map 2030 (4) calls for person-centred care and treatment approaches that prioritises country ownership and integration of services to address the long-term needs of people affected. Early case detection, disease management, disability and inclusion (DMDI) interventions should be designed to improve access to inclusive, holistic healthcare and mental health support at local (community and primary health care) levels. Additionally, the strategic framework for the integrated control and management of skin NTDs recommends that programmes should actively collaborate with people affected to acknowledge their expertise and potential and support empowerment initiatives, including peer support initiatives (5).

Community based groups (CBGs, Figure 1), also known as self-care, peer-support, self-support, self-care practice groups or self-help groups, are person-centred approaches which empower people affected by skin-NTDs to regain control of their health, increasing social participation and inclusion, resulting in "positive mental and physical health outcomes as well as belonging to society" (5). CBGs aim to empower people affected to become active participants in the management of their condition, as well as serving as forums which foster a culture of trust to support and advocate for its members on their disease journey, enhancing social participation. As Figure 2 indicates, there are two core domains of CBGs: 1) the self-management of the disease/morbidity focused on immediate outcomes; and 2) social participation and inclusion focused on mid/long term outcomes.

Prevention of disability (POD) related to NTDs has mainly been studied in leprosy and LF, although non-governmental

organisations (NGOs) are increasingly implementing, supporting, or sustaining self-care activities through CBGs, integrating other skin NTDs. Several self-care guidelines have already been published and adopted for leprosy and LF (6–9). The importance of addressing self-awareness, people-centred approaches, livelihoods, mental well-being, advocacy, and the social and broader drivers of health are increasingly recognised (10). Some interventions have adopted integrated approaches for lower limb disorders, caused by leprosy, LF and podoconiosis in CBG models (11), whereas others have demonstrated the importance of introducing mental health peer counsellors to community interventions (12). An extensive literature review on the relationship between stigma, mental health and NTDs is now available (13). Despite this review highlighting that further information is needed to understand the most appropriate intervention approaches that can be implemented at scale to improve mental health of people affected by NTDs, peer support is emphasised as a critical option (13). Finally, organisational principles and behavioural theories have also been documented in the context of self-care planning (14, 15). Overall, CBGs present a powerful and widely recognised bottom-up intervention model that aligns with the WHO's recent strategic framework for integrating skin NTDs and show potential for enhancing the upwards accountability of health systems through the empowerment of people affected. This may also allow for the development of core competencies and indicators that could be embedded within the NTD road map to support countries and programmes to attain road map goals.

Despite their evident importance, within and across countries, the operationalisation of CBG approaches is not yet integrated

*"Informal groups of people who come together to share common problems and support each other. They can address health issues, emotional needs and depression, social discrimination and livelihoods. Self-care and self-support groups must be inclusive to society as much as possible. Health workers or self-support groups may identify issues requiring them to link up with other community sectors that can facilitate daily self-care practices or participation in school, work and community life. This cross-sectoral collaboration may be with education, WASH, transportation, housing, social services, communications, construction, agriculture, governance and other sectors"*

FIGURE 1  
The WHO's definition of CBGs (source: 5).

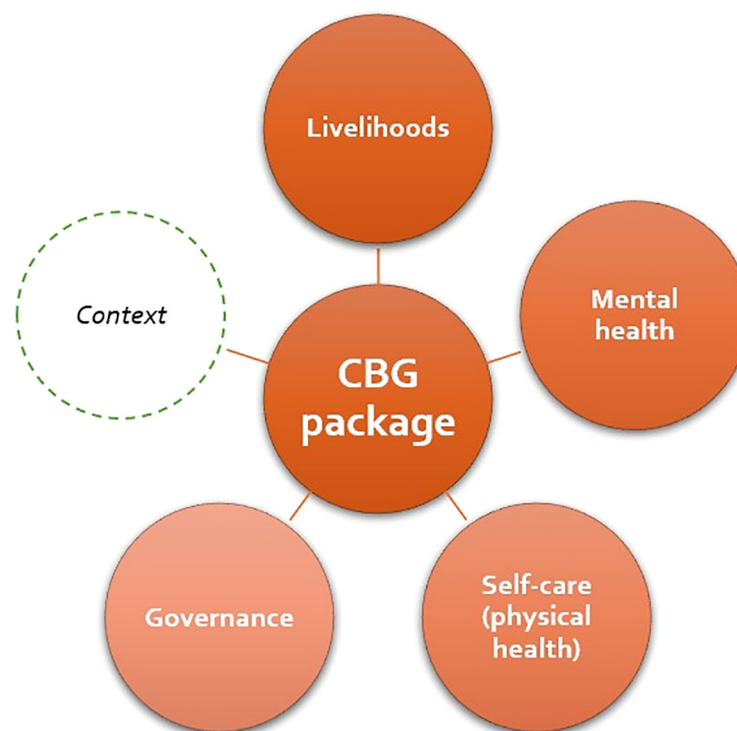


FIGURE 2  
Domains of CBG framework (source: author).

across health systems and their NGO implementing partners. Whilst contextual differences should be recognised and addressed in CBG models, it would be beneficial to formalize, harmonise and operationalise both cross-cutting theories and preferred practices to enhance effectiveness and improve sustainability. Such efforts would allow for harmonisation of impact measures, presenting the potential for cross-sectoral analysis and learning, contributing to enhanced programme planning, delivery, and monitoring, in the longer term.

The Unlocking the Potential of Leprosy & NTD affected people, to pursue Inclusive, Fulfilling and Transformational lives, through a harmonised Community Based Group model (UPLIFT) study aims to explore the function of CBGs with a view to develop a harmonised operational model for piloting across Bangladesh, Ethiopia, and India. To inform the development of a harmonised operational model, we conducted a scoping review to identify preferred practices and areas for improvement in existing CBG models, particularly those focused on leprosy, and or other skin-NTDs. We were particularly focused on understanding; CBG structure, member dynamics, needs, priority areas and approaches to self-care, mental health, livelihoods; and any other relevant consideration for operationalising harmonised CBG models.

## 2 Methods

Scoping reviews are appropriate when there is limited evidence available as they include a breadth of topics and study designs and

do not assess the quality of evidence (16). Given that we were focused on ascertaining a broad understanding of the multiple and varied ways in which CBGs have been designed, implemented and evaluated, a scoping review was deemed appropriate. Our scoping review follows the methodological framework of Arksey and O'Malley (16) and is presented according to the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines (17).

### 2.1 Data sources and search strategy

The search strategy included keywords and Medical Subject Headings (MeSH) terms related to two concepts: 1) community-based groups (CBGs) (including other common synonyms e.g., self-help groups) and 2) skin-NTDs. The strategy was developed through consultation with Alison Derbyshire, an Academic Liaison & Training Specialist at LSTM. The search strategy was piloted and refined using Medline Complete and the finalised strategy (Table 1) was run on the 2<sup>nd</sup> of March 2023 on the following databases: Medline Complete, Psycinfo, CINHAL Complete and Global Health.

Once the peer reviewed literature gathering was complete, we searched for grey literature from key organisations' websites, including Infolep, InfoNTD, the WHO and several other institutions, on the 24<sup>th</sup> of April 2023, as well as hand searching reference lists.

TABLE 1 Medline search strategy.

Search 1 terms	“community group*” OR “self-care” OR “self care” OR “self-support” OR “self support” OR “self-help” OR “self help” OR “community-based group*” OR “community based group*” OR “community support” OR “community participation” OR “social support” OR “support group*” OR “peer support” OR Community Networks (MH) OR Community Participation (MH) OR Social Support (MH) OR Self Care (MH) OR Social Support OR Community Support OR Psychosocial Support Systems
AND	
Search 2 terms	leprosy OR “hansen* disease” OR “lymphatic filarias*” OR “skin neglected tropical disease*” OR “neglected tropical skin disease*” OR “skin NTD*” OR leishmania* OR “buruli ulcer” OR onchocercias* OR yaws OR frambesia OR framboesia OR scabies OR “severe stigmatizing skin disease*” OR lymphoedema OR lymphedema podocoinosis OR elephantias* OR Leprosy (MH) OR Elephantiasis, Filarial (MH) OR Skin Diseases, Infectious (MH) OR Leishmaniasis (MH) OR Buruli Ulcer (MH) OR Onchocerciasis (MH) OR Yaws (MH) OR Scabies (MH) OR Elephantiasis (MH)

## 2.2 Eligibility criteria

Eligible studies explored community models, investigated skin-NTDs and were published in English from 2000 onwards, since the WHO published a draft 2021-2030 road map for NTDs in April 2020, increasing attention, and potentially evidence, surrounding NTDs. Studies were also eligible if they used quantitative, qualitative, or mixed method approaches, or if they entailed secondary analysis or evidence synthesis. Studies that did not explore community models through the lens of skin NTDs and were published prior to 2000 in a language other than English were excluded. As were opinion pieces, cross-sectional surveys, editorials, and individual case studies.

## 2.3 Study outcomes

Study outcomes of interest were those related to the core domains deemed as critically important based on the literature and informed by ongoing discussions with subject matter experts within the UPLIFT consortium and the DMDI working group of the NGDO Network on NTDs (Figure 2). Additionally, we also considered variations in outcome related to age, gender, and socioeconomic status, where reported.

## 2.4 Citation management

Citations from peer-reviewed literature were imported into Endnote 20 and duplicates were removed automatically and then manually, before being exported into an Excel sheet for screening.

Grey literature was entered into an Excel sheet and duplicates were removed manually. Titles were also entered into Endnote to check for duplicates with existing peer-reviewed literature.

## 2.5 Study selection

Eligible citations were identified through a two-stage screening process. First, titles and abstracts were screened to assess whether the citations were related to; 1) CBGs and 2) skin-NTDs. IH and LD double screened the first 20% and compared agreement. As a good level of agreement was achieved (defined as an inter-rater agreement of >90% (18), IH completed the rest of screening independently. Next, full texts were screened according to the eligibility criteria. IH and LD double screened the first 20% and achieved good agreement. Hence, IH screened the remainder of citations independently, with SC providing a third review to determine eligibility in cases of any discrepancies.

## 2.6 Charting

The Excel data charting form was developed according to the key CBG domains previously identified (Figure 2): basic information; study setting; participants; intervention; CBG components of intervention (self-care, mental health, livelihood, monitoring and governance); outcomes and method of measure; evaluation and findings. Once an eligible pool of studies was identified, IH and LD double extracted the first 10% of papers before comparing. As good agreement was achieved, IH and SC extracted the remainder independently.

## 2.7 Collating, summarising, and reporting

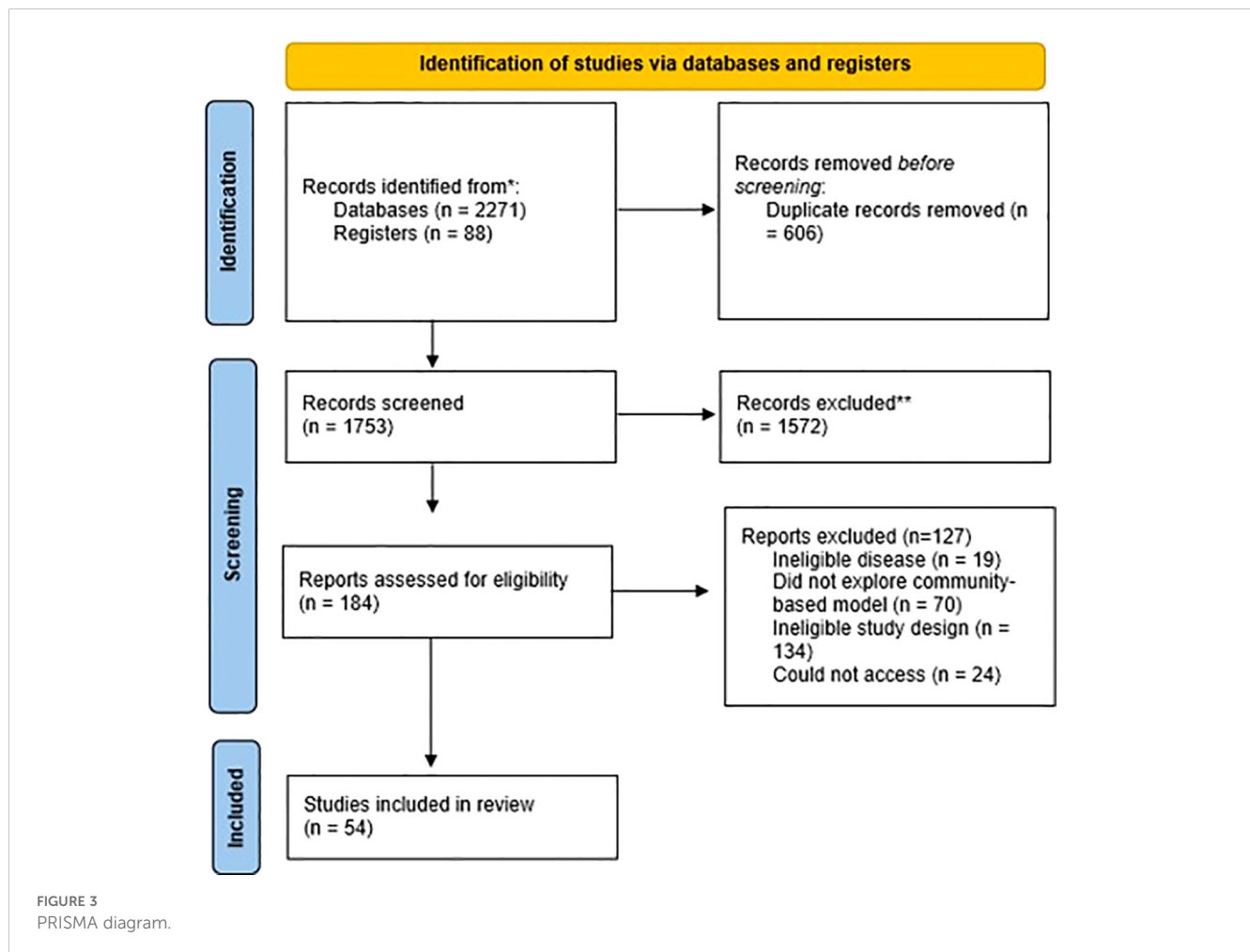
Following data extraction, study findings were synthesised and presented according to domains of CBGs identified within the UPLIFT framework in a Word document, applying the thematic analysis approach (Figure 2) (19). Additional emerging domains were also considered. The findings were written up thematically by IH and SC and reviewed by LD. Finally, the findings were explored during a set of online dissemination workshops with subject matter experts.

## 3 Results

The searches identified 2,359 citations for review, of which, 54 were deemed eligible for inclusion. The majority (n=38) were peer-reviewed papers and 17 were grey literature. Figure 3 presents a flow chart of the search, screening process and application of the eligibility criteria.

### 3.1 Study characteristics

Studies were conducted across Asia (n=20), Africa (n=16) and South America (n=2), with some focused on multiple countries



(n=3) and others having a global focus (n=8). Five studies did not describe a specific geographical focus, and most were conducted in a single country (n=38). Ethiopia was the most common country (n=8), followed by Nepal (n=7) and India (n=6). Included studies demonstrated a high degree of heterogeneity, with 17 different study designs identified. The majority were pretest/posttest designs (n=11), followed by reports (n=8) and reviews (n=7) and most used mixed methods (n=24). Most studies targeted a single disease (67%), with leprosy (n=29) being most common, followed by studies targeting LF alone (n=5) and leprosy, LF and podocniosis simultaneously (n=5). See [Table 2](#) for an overview of study characteristics.

[Table 2](#) includes information on the type of CBG domain covered and the type of formal evaluation tool used, demonstrating that across all studies, tools are not standardised and not all domains are covered. Advocacy and awareness emerged as an additional critical domain based on the evidence. Overall, just four studies discussed all five domains, including advocacy and awareness ([27](#), [46](#), [48](#), [62](#)) and eight studies did not discuss any of the key domains. Tools evaluated self-support, self-care and self-help structures (n=37), including outcomes related to physical impacts: skin and wound care (n=28), health literacy (n=3) and other outcomes e.g., referrals (n=7). Mental health was also evaluated (n=29), including tools exploring the impact of mental health and counselling (n=17) and changes in stigma reduction and social

participation (n=11). Tools were largely quantitative, with only four studies using qualitative methods, such as FGDs, interviews and photovoice to evaluate numerous outcomes ([27](#), [39](#), [57](#), [62](#)).

### 3.2 Self-support, self-care, and self-help structures

Self-care typically focused on skin/wound care and health education and was highlighted by most papers (39/54), illustrating that it is often the primary focus of CBGs.

#### 3.2.1 Skin and wound care

Wound management activities involve basic training, typically from health providers, with demonstrations on how to clean wounds using soap and water and perform self-care at home ([6](#), [27](#), [39](#), [50](#), [57](#)). For leprosy-specific CBGs, some studies highlighted inspection of hands and feet for signs of damage as central and typically entailing soaking one's hands/feet in water for 30 min, often using mud pots and a stone to gently scrape over callouses; dressing wounds using local materials and oiling the skin ([50](#)). One study reported provision of treatment such as antibiotics, ointments and painkillers, though it noted that such treatment is considerably less common ([44](#)). Where treatment is not provided,



TABLE 2 Overview of characteristics of studies included in review.

Lead author	Literature source - Peer-reviewed/grey	Country	Quant/qual/mixed	Design category	Disease category	CBG domain covered	Evaluative measure
Aggithaya et al. (20)	Peer-reviewed	India	Quantitative	Pretest-posttest	LF	Self-care	LF-Specific QoL questionnaires
Akogun and Badaki (21)	Peer-reviewed	Nigeria	Mixed	Pretest-posttest	LF	Self-care Governance	Presence of lesions, warts and skin folds Graded limb swelling WHO disability grading scales Interviewed on degree of physical pain ADL frequency, duration and odour
Arief (22)	Grey	Indonesia	Mixed	Review	Leprosy	Self-care Livelihoods Governance	–
Atinbire et al. (23)	Peer-reviewed	Ghana	Mixed	Pretest-posttest	LF	Self-care Governance	–
Benbow and Tamiru (24)	Peer-reviewed	Ethiopia	Mixed	Report	Leprosy	Self-care Governance	Presence of impairments in the eyes, hands, and feet
Bhat et al. (25)	Peer-reviewed	India	Quantitative	Pretest-posttest	Leprosy	MH Livelihoods Governance	Explanatory Model Interview Catalogue (EMIC) stigma
Celiktemur et al. (14)	Peer-reviewed	Unspecified	N/A	Article	Leprosy	Governance	–
Chowdhury et al. (26)	Peer-reviewed	Unspecified	Unclear	Review	Leprosy	–	–
Chowdhury et al. (27)	Peer-reviewed	Nigeria	Qualitative	Community based participatory research (CBPR)	Leprosy, LF and Buruli ulcer	Self-care MH Livelihoods Advocacy and awareness Governance	Referral and tracing resulting from CBGs KIIs, FGDs, participant observation, micronarratives and photovoice
Cornielje et al. (28)	Peer-reviewed	Worldwide	N/A	Article	Not disease specific	Livelihoods Governance	–
Cornielje et al. (29)	Grey	India	N/A	Article	Leprosy	–	–
Cross and Choudhary (30)	Peer-reviewed	Nepal	Mixed	Non-randomised intervention	Leprosy	Livelihoods Governance	Referral and tracing resulting from CBGs Participation Scale (P-Scale)
Cross and Choudhary (31)	Peer-reviewed	Nepal	Mixed	Posttest only	Leprosy	Governance Livelihoods	Self-reported participation
Cross (32)	Peer-reviewed	Unspecified	N/A	Article	Leprosy	–	–

(Continued)

TABLE 2 Continued

Lead author	Literature source - Peer-reviewed/grey	Country	Quant/qual/mixed	Design category	Disease category	CBG domain covered	Evaluative measure
Cross et al. (33)	Peer-reviewed	Nepal	Mixed	Descriptive	Leprosy and non-skin NTDs	MH Livelihoods Governance	Extent of Handicap Functional (EHF) score General Self-Efficacy scale Participation Scale (P-Scale)
Dahiru et al. (34)	Grey	Nigeria	N/A	Report	Leprosy	Self-care Livelihoods Governance	–
Darlong (10)	Peer-reviewed	Worldwide	N/A	Review	Leprosy	MH Governance	–
De Bruin et al. (35)	Peer-reviewed	Worldwide	Mixed	Exploratory study	Leprosy and non-skin NTDs	Self-care MH Governance	–
Deepak (36)	Peer-reviewed	Indonesia and India	Mixed	Article	Leprosy	Self-care Livelihoods Advocacy and awareness Governance	–
Dellar et al. (37)	Peer-reviewed	Ethiopia	Quantitative	Pretest-posttest	Leprosy, LF and podoconiosis	Self-care MH Governance	ADL frequency Patient Health Questionnaire-9 (PHQ-9) DLQI WHO Disability Assessment Schedule (WHODAS) Health-related QoL – DLQI Adapted Discrimination and Stigma Scale (DISC-12)
Douglass et al. (38)	Peer-reviewed	Ethiopia	Mixed	cRCT	LF and podoconiosis	Self-care Governance	Lymphedema stage Mid-calf circumference and tissue compressibility ADL frequency Days lots No. of lesions Self reported adherence (journal and interviews)
Ebenso et al. (39)	Peer-reviewed	Nigeria	Mixed	Retrospective	Leprosy	–	Interviews, KIIs and FGDs Stigma measured using P-scale
Ebenso et al. (40)	Peer-reviewed	Nigeria	Mixed	Retrospective	Leprosy	Self-care Livelihoods Governance	–
Ebenso et al. (41)	Peer-reviewed	Nigeria	N/A	Review	Leprosy	Self-care Livelihoods Advocacy and awareness Governance	–

(Continued)

TABLE 2 Continued

Lead author	Literature source - Peer-reviewed/grey	Country	Quant/qual/mixed	Design category	Disease category	CBG domain covered	Evaluative measure
Finkenflügel and Rule (42)	Peer-reviewed	Worldwide	N/A	Review	Not disease specific	Governance	–
Gidado et al. (43)	Grey	Nigeria	Mixed	Descriptive	Leprosy	Self-care Governance	Presence of impairments in the eyes, hands, and feet WHO disability grading scales
Hounscome et al. (44)	Peer-reviewed	Ethiopia	Mixed	Pretest-posttest	Leprosy, LF and podoconiosis	Self-care MH Advocacy and awareness Governance	WHO Disability Assessment Schedule (WHODAS) Foot measurement Health-related QoL – DLQI
Husada (45)	Grey	Indonesia	N/A	Report	Leprosy	Self-care Livelihoods Advocacy and awareness Governance	Presence of impairments in the eyes, hands, and feet
IILEP (46)	Grey	Bangladesh, China, Colombia, Ethiopia, India, Indonesia, Nepal	N/A	Report	Leprosy	Self-care MH Livelihoods Advocacy and awareness Governance	–
Jay (2022) Jay et al. (47)	Peer-reviewed	Nepal	Quantitative	Longitudinal	Leprosy	Self-care	Short Assessment of Health Literacy questionnaire
Jha et al. (48)	Grey	Nepal	Mixed	Posttest only control	Leprosy and LF	Self-care MH Livelihoods Advocacy and awareness Governance	General Self-Efficacy scale
Kiran et al. (49)	Peer-reviewed	Nepal	Mixed	Posttest only	Leprosy	Self-care MH Livelihoods Advocacy and awareness	General Self-Efficacy scale
Madhavan et al. (50)	Peer-reviewed	India	Mixed	Pretest-posttest	Leprosy	Self-care MH	–

(Continued)



TABLE 2 Continued

Lead author	Literature source - Peer-reviewed/grey	Country	Quant/qual/mixed	Design category	Disease category	CBG domain covered	Evaluative measure
Martos-Casado et al. (51)	Peer-reviewed	Ethiopia, India, Indonesia, Mozambique, Nepal, Nigeria, Tanzania	Mixed	Review	Leprosy	-	-
Muldoon et al. (52)	Peer-reviewed	Nepal	Quantitative	Pretest-posttest	Leprosy	Governance Self-care Livelihoods	Short Assessment of Health Literacy questionnaire SARI Stigma scale
Narahari et al. (53)	Peer-reviewed	India	Mixed	Non-randomised intervention	LF	Self-care MH	Limb volume, determined through water displacement Presence or absence of bacterial entry points (BEP) examined using McNemar test Photos of limb Frequency of ADL attacks FGDs to explore non-adherence reasons LF-Specific QoL questionnaires
Negussie et al. (54)	Peer-reviewed	Ethiopia	Mixed	RCT	Podoconiosis	Self-care Governance	Presence of impairments in the eyes, hands, and feet Cumulative incidence of ADL Self-care adherence (survey) Leg/foot circumference Presence of mossy changes, wounds and interdigital lesions Duration of ADL Validated self-reported pictorial diaries Validated podoconiosis stigma scale
Noordende et al. (55)	Peer-reviewed	Unspecified	Mixed	Review	Leprosy and non-skin NTDs	Self-care Livelihoods Advocacy and awareness	Presence or absence of bacterial entry points (BEP) examined using McNemar test
Noordende (56)	Grey	Brazil	Qualitative	Descriptive	Leprosy	Self-care Livelihoods Advocacy and awareness	
Noordende et al. (57)	Peer-reviewed	Ethiopia	Mixed	Pretest-posttest	Leprosy, LF and podoconiosis	Self-care Livelihoods Advocacy and awareness Governance	Presence of impairments in the eyes, hands, and feet Frequency of ADL attacks Screening of Activity Limitation and Safety Awareness (SALSA) Foot and length circumference Shoe wearing behavior KAP survey to assess knowledge Patient Health Questionnaire-9 (PHQ-9) Family QoL via the 25-item Beach Centre Family Quality of Life (FQoL)

(Continued)

TABLE 2 Continued

Lead author	Literature source - Peer-reviewed/grey	Country	Quant/qual/mixed	Design category	Disease category	CBG domain covered	Evaluative measure
Noordende et al. (58)	Peer-reviewed	Ethiopia	Mixed	RCT	Leprosy, LF and podoconiosis	Self-care MH Livelihoods Governance	Interviews and FGDs Patient Health Questionnaire-9 (PHQ-9) Social participation measured with P-scale SARI Stigma Scale (SSS) Monthly house Monthly contribution to SHG SARI Stigma scale
Oktavian et al. (59)	Grey	Indonesia	Unclear	Descriptive	Leprosy	Self-care	–
PAHO (60)	Peer-reviewed	Worldwide	N/A	N/A	Leprosy, skin NTDs and non-skin NTDs	Governance	–
Pronk et al. (61)	Grey	India, Bangladesh, Indonesia, Nepal, Mozambique, Liberia, Cote d'Ivoire, Nigeria, Democratic Republic of Congo and Brazil	Quantitative	Report	Leprosy and LF	Advocacy and awareness	–
Sermrittirong et al. (62)	Grey	Thailand	Mixed	Pretest-posttest	Leprosy	Self-care MH Livelihoods Advocacy and awareness Governance	Interviews and FGDs on accessibility of care, impact of stigma on QoL and perceptions of PAL The Explanatory Model Interview Catalogue (EMIC) stigma scale
Shrestha et al. (63)	Peer-reviewed	Nepal	Mixed	Cohort study	Leprosy and LF	Self-care Livelihoods Advocacy and awareness Governance	European Quality of Life 5 Dimensions 3 Level Version (EQ5D-3L) Physical inspections Ulcer metrics via photos Subjective wellbeing was measured using a 5-question instrument, adapted from Van Brakel (2006) Participation Scale (P-Scale) was
Souza et al. (64)	Peer-reviewed	Brazil	Qualitative	Observational study	Leprosy	–	–
Susanto et al. (65)	Peer-reviewed	Indonesia	Qualitative	Descriptive	Leprosy	–	Interviews on treatment, HSB and caregiver expectations
TLM (66)	Grey	Unspecified	N/A	N/A	Leprosy	Self-care	–
TLMTI (67)	Grey	India	N/A	N/A	Leprosy	Livelihoods Governance	–
Tora et al. (68)	Grey	Ethiopia	Qualitative	Process evaluation	Leprosy, LF and podoconiosis	Advocacy and awareness Governance	–

(Continued)

TABLE 2 Continued

Lead author	Literature source - Peer-reviewed/grey	Country	Quant/qual/mixed	Design category	Disease category	CBG domain covered	Evaluative measure
WHO (4)	Grey	Worldwide	N/A	Report	NTDs including skin NTDs	-	-
WHO (5)	Grey	Worldwide	N/A	Report	Skin NTDs	Self-care MH Livelihoods Advocacy and awareness	-
WHO (69)	Grey	Worldwide	N/A	Report	NTDs including skin NTDs	MH Governance	-
Yahathugoda et al. (70)	Peer-reviewed	Sri Lanka	Quantitative	Pretest-posttest	LF	Self-care	Limb volume, determined through water displacement ADL frequency Photos of limbs and skin hygiene Presence of ADL KAP survey to assess knowledge Modified Dermatology Life Quality Index (DLQI)

members are typically referred to government clinics where they can access medicines, as described by Yahathugoda et al. (70).

According to Noordende et al. (57), CBG members typically receive self-care kits to practice self-care, such as soap, bandages, Vaseline, and buckets. CBGs focused on leprosy, LF and podoconiosis also provide protective footwear, which is occasionally custom-made, as highlighted by a few studies (35, 44, 45).

Where CBGs cannot provide medication, the focus is on prevention using local material(s) (including soap and oil); Benbow and Tamiru (24) places emphasis on finding local solutions through the self-provision of materials where group members are required to provide their own wound management materials. This self-reliant approach encourages individuals to take ownership of their healing process and prevents reliance on external sources (24). Local materials included the core from a maize corncob as a scraping tool and cellulose strips from the stem of the banana leaf as bandages (24).

### 3.2.2 Health education

Health education includes information on conditions, symptoms, and environmental factors, as well as treatment, hygiene, and exercise and is key in achieving behaviour change – a domain of interest in the NTD community. Some CBGs use Information Education Communication (IEC) materials to educate patients on management procedures to be followed up at home; it is recommended that IEC materials on conditions, skin and wound care are pictorial and written in local languages (27, 44, 62). Yoga exercises were facilitated in LF camps in India focusing on flexion of toes, ankle joints and breathing exercises (20). As Noordende et al. (57) highlights, facilitation of self-support techniques is often cascaded; for example, the first meetings are often facilitated by health workers, who then supervise members and carers on techniques. Several studies described how family members and caregivers are often involved in training on self-care highlighting their key role in the support and recovery of CBG members (10, 23, 28, 39, 42).

### 3.3 Mental health and stigma reduction interventions in CBGs

Despite a growing recognition of the importance of addressing stigma and mental health through CBGs, only 16 studies included mental health components, typically focused on uniting people affected and their communities and providing mental health support, such as counselling (5, 10, 22, 25, 27, 33, 35, 37, 44, 46, 48–50, 53, 58, 62, 69).

We have included all references to any form of counselling or talk therapy within this section as we recognise that understanding of disease causation is critical to supporting good mental health amongst people affected (71). The content of CBG counselling activities reported by studies varied and included providing accurate disease knowledge, addressing misconceptions around the cause of conditions (e.g., that skin NTDs are caused by witchcraft or curses which are self-inflicted), as well as facilitating discussions around emotions and relationships in relation to stigma and coping mechanisms (25, 33, 35, 46). Typically, encouraging

members to share their personal experiences and success stories, fosters belonging and strengthens social connections between group members, as highlighted by Bhat et al. (25) and Chowdhury et al. (27).

According to the WHO (5), CBGs and peer supporters play a crucial role in addressing mental health and stigma, due to their deep understanding from lived experience. Individuals can be educated in basic techniques like psychological first aid (PFA) and facilitating prompt referrals to specialised services, enabling early identification of mental health conditions (5). According to Noordende et al. (57), people affected and families learn about receiving and providing psychosocial support. In Ethiopia (EnDPoINT study), a mental health professional conducted assessments for all patients, treatment (e.g., counselling and antidepressants) were administered if required, and caregivers received guidance on administering medication (37). Follow-up consultations with mental health experts were also scheduled. Prescribers, local nurses and health officers also received a 5-day training course in DMDI and mental health (37). Mental health training was guided by the WHO Mental Health Gap Action Program resources and involved a 5-day practical in a hospital, facilitated by a psychiatrist, as well as supervision and mentorship (37). Studies in Nepal also emphasised that integrating mental health services improves the efficiency and cost-effectiveness of community-based groups, strengthening wellbeing and adherence (5).

### 3.4 Livelihood and economic empowerment

Twenty-five studies included livelihood and economic empowerment (5, 22, 25, 27, 28, 30, 31, 33, 34, 36, 40, 41, 45, 46, 48, 49, 55–59, 62, 63, 67, 72). The WHO (5) highlights livelihood activities, specifically financial activities, as a key form of self-help for people affected and their family members. According to Cornielje et al. (28), socioeconomic empowerment stops the cycle of poverty, dependence, and isolation, through improving self-perception and social status, though CBGs should refrain from focusing solely on socioeconomic rehabilitation as such programmes would fail to address other key domains. Twenty (20) of the studies included livelihood components.

#### 3.4.1 Micro credit and micro loans

According to ILEP (46), CBGs typically act as “micro credit unions” wherein members make small financial contributions (e.g., 10 taka/month or 0.08 USD/month) into a communal pot of money, which NGOs might also contribute to. Whilst the facilitator (see section on Facilitation: roles and responsibilities below) typically safeguards funds, decisions on who obtains loans and interest rates tend to be a group decision, potentially dependent on members fulfilling pre-requisites e.g., financially contributing for 6 months, as described by Dahiru et al. (34). Alternatively, in Ethiopia, implementers established Organisations for People with

Disabilities (OPDs) for each skin-NTD, providing microfinance via member contributions (57).

One typical use of micro-loans is seed money for micro-enterprise development (30); with support from CBGs, people affected launch businesses such as traditional handicraft shops; fish or chicken farms and traditional medicine stores, as described by a few studies (34, 46, 62). This is achieved through vocational training and skills programmes on topics such as literacy, bamboo weaving, farming, marketing and packaging production, as well as general business skills, in some studies (27, 34, 46, 52, 62, 67). As Muldoon et al. (52) described, CBGs also provide training to family members, on the basis that “income generation will benefit the whole family”. Micro-enterprise development typically occurs in the maturation phase, once the CBG has achieved significant improvements in health and hygiene practices, according to Dahiru et al. (34). Some papers assert that aside from improving the financial and social status of people affected and their families, these activities support the local economy and enable people to re-train in professions which are less physically demanding, also improving family relationships (34, 67, 72). In addition to encouraging new business formation, organisations such as The Leprosy Mission India focus on nurturing existing enterprises through adoption of innovative approaches e.g., rainwater harvesting (67). Additionally, CBGs might support people affected to seek appropriate employment from existing businesses (67).

#### 3.4.2 Community development

Another key livelihood activity is community development, which generally occurs in the CBG growth phase (~five years in, when there is a shift towards community interventions and participation and self-advocacy) (41). Grounded in concepts of civic responsibility, some studies describe CBGs encouraging participation in community enhancement activities, such as road repair and improving water, sanitation and hygiene (WASH) infrastructure (30, 33, 46). Additionally, members might organise informal education and health promotion activities, such as street dramas, as well as supporting community development activities for other marginalised groups, as described by Cross et al. (33) and Kiran et al. (49). Such activities might entail engaging community leaders and government to conduct formal needs assessments, as in the case of TLMTT's CBGs, federations and cooperatives (67). As Ebenso et al. (41) highlight, the level of success is largely dependent on the planning stage and active participation of communities of people affected.

### 3.5 Advocacy and awareness

Seventeen (17) studies included advocacy and awareness focused on: 1) the rights of people affected by skin-NTDs, as well as other members who may be vulnerable to discrimination and exclusion, such as older people; 2) improving access to healthcare and infrastructure; and 3) evidence based NTD action and equal access to opportunities, such as employment and essential services

(5, 27, 30, 36, 41, 44–46, 49, 53, 55–57, 61–63, 68). Advocacy objectives were achieved through holding forums and public functions with social and political leaders in India (53), school visits in Bangladesh (46), district department visits in Indonesia (46) or through providing advocacy training to patient advocacy groups (46). One prime example of successful advocacy efforts is in Nigeria, where the growth phase of an intervention witnessed the formation of the Nigerian International Association for Integration, Dignity and Economic Advancement (IDEA) – groups which advocate for the rights of people affected by leprosy (41). Through self-advocacy campaigns, IDEA have achieved “chapters” or groups in almost all states (41).

Advocacy typically involves collaboration with numerous intersectional stakeholders, such as the Ministry of Health (MoH), community and religious leaders, national NTD programmes, NGOs/international MGOs, female community volunteers, healthcare staff, organisations of people with disabilities and schools, as described by a few studies (27, 46, 61, 63).

Awareness raising amongst communities and affected populations was identified as crucial in addressing stigma, increasing acceptance and ensuring early diagnosis of skin-NTDs by Noordende (56) and the WHO (5). Activities typically included: the design and distribution of IEC materials including posters, videos, mass media and comics; training for community volunteers; community awareness workshops and exhibitions in health centres and communities (36, 44, 46, 62). Awareness topics included the early signs of skin-NTDs, myth busting and promoting positive attitudes during ‘contact events’ with community members, as described by Noordende (56). One example of groups setting expectations regarding awareness raising was seen in Ethiopia, where members are expected to deliver health information to a minimum of five community members each month, via community social events (68).

## 3.6 Governance: behavioural, organisational and structural considerations

The exact structural organisation of CBGs and the various roles and committees was shaped by the group’s purpose, e.g., whether focused on self-care or livelihoods (73). Key considerations identified in the literature were group size, meeting schedules, meeting venue and facilitation process. Some authors emphasised that contextual factors such as geographic barriers, lack of resources, and political instability could impact the success of support groups (28, 45, 56).

### 3.6.1 Group size

From the literature, group size varied from 5-10 members (21, 24, 34, 45, 46, 69) and 20-30, which was less common (27, 43). As Dahiru et al. (34) highlights, groups should be big enough to encourage discussions, but not so big that members grow bored waiting for their turn to speak or be examined. Size depends on numerous factors, including location - Benbow and Tamiru (24) found groups in rural areas were typically half the size of urban

areas, potentially due to transportation barriers. Husada (45) identifies that if group size becomes too large, reorganisation to sub-groups based on geographic location, profession and disability status is advisable. Nonetheless, it is important to ensure inclusion of women during group formation and establishing group leadership as women are often neglected due to their “less visible role in society” – for instance, Shrestha et al. (63) recommend ensuring that at least 50% of leadership are women (45, 63). According to Noordende et al. (57), many CBGs also invite family members or neighbors to participate.

### 3.6.2 Meeting schedule

The frequency and timing of meetings is dictated by members, and ranges from weekly to trimonthly, with monthly sessions being most common (8/19 studies reporting the frequency) (24, 27, 33, 45, 54, 58, 59, 62). As Husada (45) highlights, meeting more frequently initially helps build rapport quickly and using dates like “every first Thursday of the month” is most memorable and holding meetings on market days supports members to combine trips, saving on travel. Weekend meetings may need revision if members are employed (45). Moreover, the timing of meetings might need to be adjusted seasonally – for instance, Dahiru et al. (34) asserts that evening meetings will be preferable during farming session.

Meetings typically last 1-2 hours, and CBG duration spans from weeks-years, depending on funding availability, disease severity, group demand and meeting frequency (24, 45, 63). Husada (45) reports that once the group has reached the end of its planned duration, there are several options for next steps, including a) terminating the group b) continuing with a reduced frequency or c) continuing in the same fashion. The latter may require groups to seek alternative funding sources.

### 3.6.3 Meeting venue

According to the literature, meeting places are generally selected by group members; typical locations include health centres, people’s homes and public or private community locations (24, 33, 34, 46). Whilst the latter fosters a sense of community and encourages involvement from family and neighbors, Husada (45) warns that holding meetings publicly may expose members to stigma. Venues must be accessible, central (members are seldom willing to pay for transport), private and large enough for everyone to sit in a circle, according to Dahiru et al. (34) and Husada (45). The same papers also suggest that venues be private, sheltered and have a water supply, as well as being close to a referral hospital (34, 45).

### 3.6.4 Facilitation: roles and responsibilities

Facilitation within CBGs refers to the role of leaders (elected group member with lived experience) and facilitators (non-group member, e.g., staff of NGO or research team implementing CBGs) in guiding and managing group dynamics, ensuring effective communication and engagement of members. The specific roles and responsibilities of facilitators and leaders varied depending on the context and the type of support group. However, leadership qualities, including an understanding of self-care, ability to assess members’ abilities, empathy, good listening skills, and a commitment

to engaging members are consistently highlighted in several papers (10, 14, 30, 45, 60). Deepak (36) notes a shortage of mid-level healthcare workers skilled in Community Based Rehabilitation (CBR), defined as an “approach and an attitude towards rehabilitation whereby people with disabilities and caregivers define their own needs and negotiate with rehabilitation workers and policymakers to improve their living circumstances and to play their full part in society” (28, 74) as a key challenge when assigning roles and responsibilities. Benbow and Tamiru (24) and Husada (45) warn that facilitators may face challenges in maintaining group dynamics, dealing with dominant members, and addressing competing priorities.

The literature highlights two primary methods for selecting or electing group leaders: 1) at point of group formation based on leadership skills; and 2) once the group has been established (58). Some studies emphasise that groups consider gender, particularly in relation to women’s representation in leadership roles; groups should strive to elect female facilitators and empower women through providing education and job training (48, 64, 75). Doing so may address the phenomenon where gender norms, cultural beliefs, and gender dynamics can pose barriers to participation and empowerment, especially for women, as highlighted in a few studies (48, 64).

Facilitators are chosen by group leaders and members; they must possess the skills and knowledge to deliver tailored awareness and stigma reduction workshops on key topics (e.g., wound management) in the local language (14, 34, 44, 63). According to Dahiru et al. (34), facilitators often receive training on their roles, wound management, group facilitation, and self-care functioning, via presentations, discussions, group work, and role play. The exact role varies, but facilitators typically bridge the gap between the leprosy programme and community, through advocating for group members and engaging community leaders, religious figures, and volunteers (21, 63). Crucially, facilitators help group members to identify problems and develop solutions, emphasising self-reliance and problem-solving within the group. Finally, they ensure understanding of the group’s objectives, monitor attendance, and guide discussions on relevant topics, as highlighted by Darlong (10).

Groups also invite external facilitators from NTD and community programmes, typically chosen by group leaders and members, to deliver training and awareness, as described in a few papers (22, 25, 27, 37).

The end goal is for people affected to eventually adopt the facilitator role entirely, no longer needing external facilitators. Therefore, external facilitators must assess the stage of the group and respond appropriately; for example, in a study in Indonesia, the district leprosy supervisor and leprosy field worker led facilitation for 2-3 meetings then facilitated election of a group leader amongst members (22, 61).

### 3.7 Monitoring and evaluation

Twenty-one (21) studies included information on monitoring and evaluation (M&E) (10, 14, 21, 23, 24, 27, 29, 33, 34, 37, 38, 42, 44–46, 50, 52, 53, 61, 62, 68, 75, 76). Across studies, the frequency of monitoring activities varied; Dahiru et al. (34) warns that M&E activities should be limited to avoid sustainability issues, suggesting

that facilitators conduct monthly visits, whilst coordinators and project leaders visit quarterly and annually.

Dahiru et al. (34) and Husada (45) identified that monitoring activities consider a range of outcomes, such as group dynamics, social participation, group size, development stage, governance structures, self-worth, and social status. Compliance and attitudes towards self-care practices are other key outcomes which can be measured via meetings and household visits, as described in a few studies (21, 33, 34). Physical improvements are often monitored via regular measurement check-ups and completion of monitoring forms or participant files by facilitators, according to Benbow and Tamiru (24) and Narahari et al. (53). Alternatively, Tora et al. (68) highlights that facilitators might directly report to an NTD focal person or there may be an elected health worker who attends meetings and monitors patient data. Hounscome et al. (44) also monitored the quality of care provided via a community advisory board formed of various stakeholders, including health professionals.

Formal evaluations, typically conducted by facilitators or medical professionals, are key in ensuring CBGs are effective and adapt to the needs of affected populations, as highlighted by Celiktemur et al. (14) and Dahiru et al. (34). Dahiru et al. (34) also cautions that activities must be constructive, focusing on identifying solutions, rather than finding fault, asserting that evaluations focus on ulcers, referrals, the group development stage, the effectiveness of the leader and members’ attitudes towards the group, among other factors.

Formal evaluation approaches vary; in Thailand, evaluations occurred at the 5- and 12-month mark and involved stakeholder engagement, capacity building to assess skills and knowledge, meetings with healthcare staff and process management and structure assessments, to evaluate participants’ understanding of tasks and roles, as well as the coordinators competency (62). In Indonesia, facilitators evaluated the impact of the CBG at 6- and 12-months, collecting data on indicators including “proportion of members who demonstrate a positive change in self-care” (45). Higher level evaluations might also include meetings between project coordinators and managers to assess CBG’s ongoing challenges and successes, as described by Dahiru et al. (34).

Formal supervisions, typically provided by NGO staff or experienced facilitators, are another important component highlighted in the literatures, which provide opportunities for facilitators to seek support and raise issues, as well as enabling DMDI knowledge assessments (23, 24).

### 3.8 Sustainability

Thirty (30) of the studies explicitly referred to sustainability (4, 5, 15, 21, 24, 27, 28, 34–36, 40–43, 45–47, 50, 51, 54–58, 60, 61, 63, 67, 69, 77), whilst an additional 13 studies included information related to sustainability without being explicit. Finkenflügel and Rule (42) argue that the movement towards CBR, specifically CBGs, presents a sustainable, person-centred approach to supporting people affected by skin-NTDs (42). Within CBGs, professionals take on a facilitative role, imparting skills and knowledge to members and their families/caregivers, enabling long-term DMDI.



This, combined with the shift of decision-making power from professionals to people affected, strengthens empowerment and self-efficacy, enabling genuine participation of people affected – key to sustainability (30, 33, 36, 60). However, some argue that self-care groups are fundamentally unsustainable in the long-term, citing accessibility challenges, such as financial and geographical constraints (39, 51, 56). According to Bassey Ebenso et al. (39), long-term sustainability of CBGs is dependent on three concepts: 1) continuity of impact; 2) participation of affected populations; and 3) mobilisation of multisectoral partnerships to achieve continuity of CBR services – we explore these below.

### 3.8.1 Continuity of impact

To enable continuity of impact, Cornielje et al. (28) assert that solutions must be manageable and financially sustainable for people affected. Instead of distributing medical provisions, many CBGs take sustainable approaches to wound management, using locally available materials, such as banana leaves and old clothes, as described by Benbow and Tamiru (24) and Narahari et al. (53). Doing so reduces financial strain and dependence on hospitals and ensures that self-care practices are sustainable and culturally relevant (24, 43). Similarly, Oktavian et al. (59) reports that many CBGs use locally available materials for producing crafts, such as recycling rubbish for income generation. Financial sustainability is also key; through livelihood projects, member contribution fees and community driven financial opportunities, CBGs can fund activities such as microloans and transport costs, as described in a few studies (5, 46, 58). Similarly, PAHO (60) emphasise that actors consider the potential impacts of external funding on long-term sustainability. In terms of potential challenges, Sermrittirong et al. (62) warned that funding for support groups may be insufficient and asserted a lack of ownership and accountability in some formal support groups might hinder the continuity of impact. Some studies also emphasised that moving towards a CBR approach requires collaboration among various ministries and stakeholders, and low awareness of morbidity management and disability prevention also poses challenges (36, 42).

### 3.8.2 Participation of affected populations

Numerous approaches to achieving participation of people affected by NTDs were identified in the review, united by an emphasis on achieving bottom-up participation from the outset through transferring power to affected populations (29, 47). Four studies identified that this could be achieved through using participatory action research during programme design; employing people affected; co-designing training and encouraging active participation in analysing findings (14, 27, 29, 63). Providing training in areas such as public speaking and note-taking also encourages ownership, as described by TLMTI (67). According to Husada (45), the long-term goal of all CBGs should be complete independence. As Cross and Choudhary (30) highlight, once self-care groups have matured, they can transform to self-help groups, which typically entails integration of livelihood activities and other marginalised groups, as well as engaging in community development and potentially transforming to an NGO. In

Bangladesh, ILEP self-help groups successfully transformed to community-based organisations, legitimising the group and enabling formation of formal programmes, ultimately increasing influence (46).

### 3.8.3 Mobilisation of multi-sectoral partnerships to ensure continuity

PAHO (60) emphasise the importance of harnessing existing structures and resources to strengthen coverage and sustainability, of CBR, as well as mobilising invaluable contextual knowledge. As Ebenso et al. (41) highlight, CBGs do not operate in isolation and hence, “continuity of activities is dependent on building stable stakeholder partnerships”. According to a few papers, to be successful, actors must foster partnerships with key stakeholders, such as OPDs, government, community-based actors, NGOs and religious institutes (30, 36, 44). Many papers suggest that participation should be supported through system strengthening activities; for example, providing capacity strengthening for MoH staff, supporting patient advocate groups and strengthening referral routes (50, 61). Integration is also key and may entail integrating NTDs with other developmental areas, such as gender and WASH or integrating other marginalised groups into CBGs, as described by Pronk et al. (61) and Shrestha et al. (63). Some studies advocated for the integration of other disabilities within skin-NTD CBGs, and skin-NTD specific services, with the aim that doing so will reduce stigma and strengthen sustainability (35, 60). Cornielje et al. (29) asserts that this “twin track approach” could enrich mainstream programmes and vice versa, with the added value strengthening sustainability. In terms of potential challenges, Cornielje et al. (29) warns that government programmes may be fragmented, with limited integration between sectors and high turnover of staff, affecting commitment and coordination, in addition to competing priorities from other developmental programmes, also highlighted by Shrestha et al. (63). Pronk et al. (61) recommends targeting multiple diseases based on commonalities between diseases (e.g., LF and leprosy) or in terms of which diseases are most prevalent in target populations.

Despite its evident importance, many CBGs fail to fully consider sustainability, as highlighted in reviews from Noordende et al. (55) and (51), which both found that sustainability was scarcely considered and called for programmes to strengthen sustainability outcomes.

#### 3.8.3.1 Linkages and collaboration with health system and government NTD programmes

Thirty-one (31) studies referenced establishing linkages with the healthcare system in multiple ways, including: collaborating with healthcare professionals and institutions to provide training, counselling, and support to group members (36); referrals to healthcare facilities, including for mental health support (44); accessing patient lists to invite them to join CBGs; and enlisting health workers, including community health workers (CHWs), as supervisors or facilitators (27, 33, 43–45, 59). For example, in a study in India, Accredited Social Health Activists (ASHAs) played a key role in bridging the local community and public health system, receiving training on administration of assessment tools and self-

care techniques (20). Whilst health staff have a role within CBGs, some papers emphasised that their roles should shift to become facilitative, rather than prescriptive (40, 58).

Similarly, linkages with government NTD programmes were highlighted in 19 studies, with MoH and NTD programmes typically being implementing partners (24, 27, 41). The roles of NTD or Leprosy-TB programmes was mainly to support referrals; emphasise government commitment to the inclusion of people affected in wider society (24, 27, 43) and to facilitate monitoring activities within routine supervision structures (23).

## 4 Discussion

This scoping review sought to map existing practices in the delivery of CBG models for skin-NTDs, with an aim to develop recommendations for a more harmonised, holistic person-centred approach to peer-support group interventions. Current approaches to CBG delivery present a powerful, person-centred approach to attaining the WHO's strategic plan for the road map for NTDs 2021-2030, which includes strategic plan to improving morbidity, enhancing participation and inclusion of people affected by skin-NTDs, as well as presenting opportunities for case identification/control/elimination of skin-NTDs. However, we highlight that further evidence is needed to understand best practices that can support sustainability, health systems integration, gender mainstreaming, mental health, stigma reduction and advocacy/awareness within current CBG approaches. Whilst most studies included components on DMDI and education and the review highlights the positive impact of CBGs on mental health, only 30% (n=16) included formal mental health support. There is growing evidence on the impact of providing talk therapy, basic PFA and facilitating mental health referrals among other NTDs. Skin-NTDs, acknowledged as one of the most stigmatised NTDs impacting populations with inadequate access to services, should follow suit and incorporate formal mental health services in CBGs (78, 79). Livelihood and economic rehabilitation activities are vital in breaking the cycle of poverty, isolation and dependence and achieving participation and inclusion of people affected; whilst there were some strong examples of micro-enterprises and credit unions, they were only in 37% of studies (n=20). Similarly, advocacy and awareness activities which are integral in driving acceptance, empowerment and case detection, were only described in 31% (n=17). This implies that components integral in reducing the burden of skin NTDs and achieving meaningful participation and inclusion of people affected are not being considered in most CBGs. Therefore, we propose an integrated CBG model that can be operationalised to overcome these gaps and drive progress towards achieving the WHO's 2030 NTD road map.

### 4.1 Framework of best practice – harmonised and holistic CBG model

Below we present a theory of change for the framework of best practice with the hypothesised outcome of each domain, its associated

outputs and related activities (Figure 4). The framework is informed by the scoping review findings as well as subsequent discussions with subject matter experts during dissemination workshops, wherein the findings and implications of the review were explored.

### 4.2 Evidence is misaligned with the burden of skin NTDs

Most studies were conducted in Asia and focused on a single country, with India, Nepal and Ethiopia being most common. Whilst there is a considerable burden of skin NTDs in these countries, especially Ethiopia, our review highlights a lack of research in the African region which accounts for the highest global burden of skin-NTDs (2). The coast of Western Africa and parts of Central Africa, the horn of Africa and Yemen, are all co-endemic for 5+ skin-NTDs. However, only 16 of the 54 studies were conducted within these regions. Moreover, there was an uneven distribution within these regions, with most conducted in Nigeria and or Ethiopia (n=10), two in Mozambique and only one study in Liberia, Côte d'Ivoire, DRC, Tanzania, and Ghana, demonstrating gaps in the evidence-base. This speaks to well-known pattern of skin-NTDs sitting low on research agendas and scientific research in Africa being consistently under-represented, due to inequitable funding, inflexible institutional frameworks, and publication bias, among other factors, which may hinder the WHO's road map progress (80–82).

Similarly, most studies focused on leprosy alone, which illustrates a lack of integration and does not reflect the burden of leprosy relative to other skin NTDs (2). This disparity is likely due to leprosy having a deep historical focus on these types of approaches, which may reflect the geographical distribution of papers (83). Regardless, it is critical that we think beyond leprosy to achieve integration and reflect the true burden of skin-NTDs, to achieve the WHO's global road map targets.

### 4.3 Integration and collaboration are crucial

Integration is central in maximising impact and achieving the WHO's road map targets; pillar 2 specifically calls for enhanced cross-cutting approaches through integrating interventions for multiple NTDs and mainstreaming of programmes into the national health system and existing programmes, to enable scaling of interventions (2). Integration enables implementation of centralised, sustainable, holistic programmes which achieve more effective use of resources, improved coverage and encourage holistic integrated approaches through harnessing synergies across existing programmes (4, 84). Moreover, integration overcomes issues of duplication and competition over resources, commonly associated with vertical programmes – ultimately, strengthening impact and health outcomes (82). Despite this, our review found that only 10 of the 54 studies targeted multiple skin-NTDs, with Leprosy, LF and podoconiosis most integrated, since these lower limb disorders share similar care needs (11, 85). Moreover, whilst the majority did collaborate with health systems and government NTD

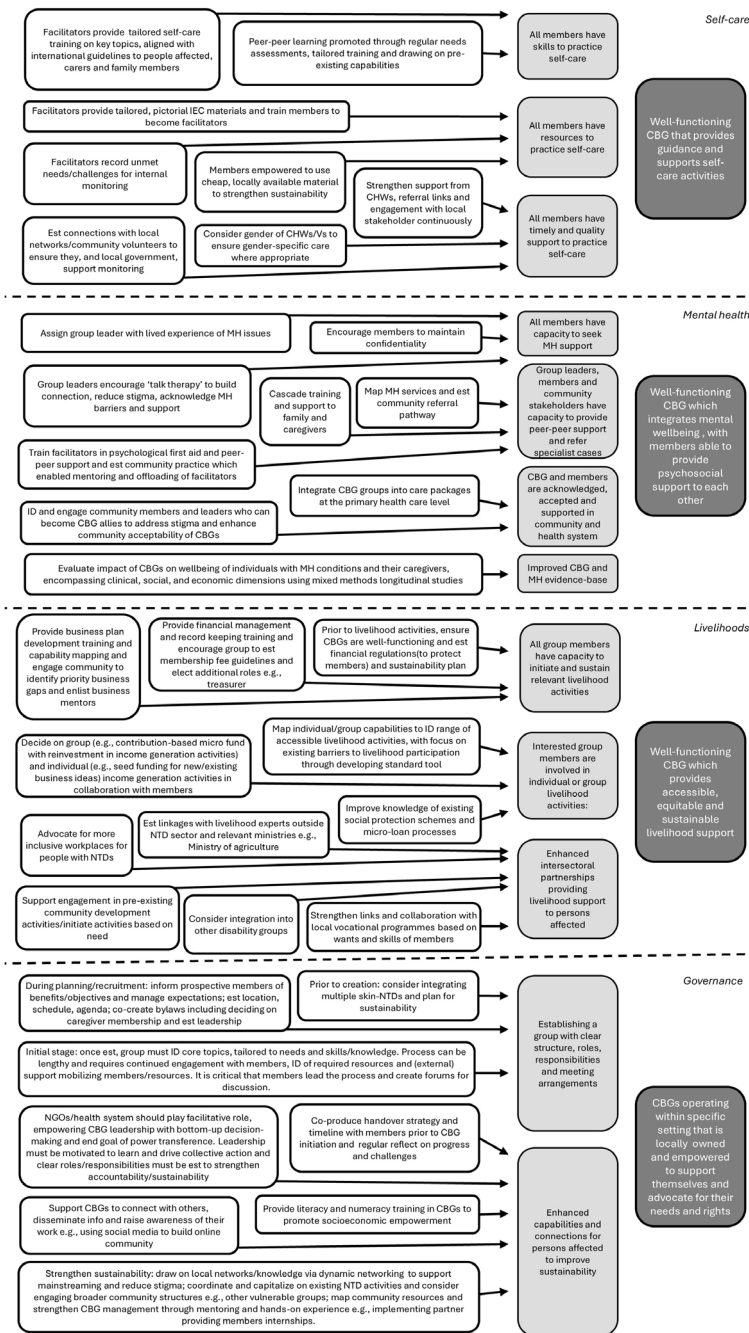


FIGURE 4 Theory of change for a framework of best practice - harmonised and holistic CBG model.

programmes, for instance through arranging two-way referrals (between CBGs and the formal health system) and enlisting health workers as external facilitators, none of the CBGs appeared to collaborate with the informal sector, such as traditional and faith healers and many relied on NGO partners to kick-start or fund such initiatives. This presents a missed opportunity for collaboration, as the role of traditional and faith-based healers in healthcare provision has gained increasing recognition over the last decade, particularly in Africa, where the burden of skin-NTDs is most severe (84, 86). There is a growing pool of literature which

demonstrates how CBGs can offer useful platforms for other NTD interventions (e.g., mass drug administration and bed net distribution), enhancing equity of delivery, particularly if they are well established within the community health system (77, 87). However, very few studies discussed this concept; where it was mentioned, it was limited to recommendations for future research, with no examples of integration in practice identified, suggesting a knowledge gap (4, 29, 35, 61).

Integration and mainstreaming are essential in achieving sustainable, locally-led CBGs and align with WHO's road map

indicator of 40 countries adopting and implementing integrated skin-NTD strategies by 2030 – thus, future CBG interventions must be integrated (4). To achieve integration, further research is needed to evidence different approaches for integration and the roles and responsibilities of different actors across the health system. The latter is particularly important, since skin-NTDs have far reaching impacts beyond the physical and psychological symptoms, which interact with virtually all aspects of people affected lives (e.g., livelihoods). Thus, cross-sectoral collaboration is key in delivering complex development interventions.

#### 4.4 Evaluative measures and study designs must be *harmonised* to improve *generalisability*

Globally, skin-NTD data is insufficient; a recent conference uniting researchers and WHO members prioritised producing strong evidence on the cost-effectiveness of DMDI for skin NTDs to support national implementation and attract donors, as well as collecting more robust data on skin-NTDs to map disease distributions and overlaps to support advocacy efforts and resource allocation (88). These aims align with WHO's road map targets of integrating M&E efforts, which remain fragmented (2). We found a high degree of heterogeneity in the study designs and measures used to evaluate the impact and effectiveness of CBGs, with very few harnessing participatory methods to capture the views and experiences of people affected. This is problematic given the limited evidence currently available on preferred practices and pathways to empowerment for people affected by NTDs. Given the centrality of DMDI, and the inclusion and participation of people affected by NTDs within WHO's NTD road map, establishing indicators of best practice/impact of CBGs is essential to enable national programmes to measure gains in these areas, and is critical to ensuring equitable and sustainable attainment of road map goals. Only one of the papers identified within this review used a randomised controlled trial (RCT) design. Going forward, we need more CBG evaluations which use robust, homogenous study designs, with standardised evaluative approaches aligned with WHO indicators to enable comparison and ensure transparency, adaptability, and accountability to affected populations.

#### 4.5 Gender is a key barrier that must be addressed

Gender is a key consideration for skin-NTDs, as it interacts with other identity factors and forms of discrimination to influence the degree of vulnerability to- and experiences of- skin NTDs, with women and girls bearing a disproportionate burden (89–91). For instance, women and girls face heightened rates of stigma and mental health issues, combined with lower educational attainment, relative decision-making power and socioeconomic inequities. These barriers significantly hinder their participation, including within CBGs. (92, 93). Thus, gender equity is a key consideration within pillar 1 of the road map for NTDs 2021-2030 'Accelerating

programmatic action' (2). Very few studies explored the gender dimension of CBGs; those that did emphasised the need for gender equity, including recruiting women facilitators in CBGs, offering education, job training, and basic services to empower women (48, 51, 64, 75). This aligns with the gap in intersectional, gender-sensitive NTD evidence described by the WHO (2) – therefore, further research is needed into the best approaches to mainstream intersectional, gendered considerations within CBG models.

#### 4.6 Sustainability is fundamental

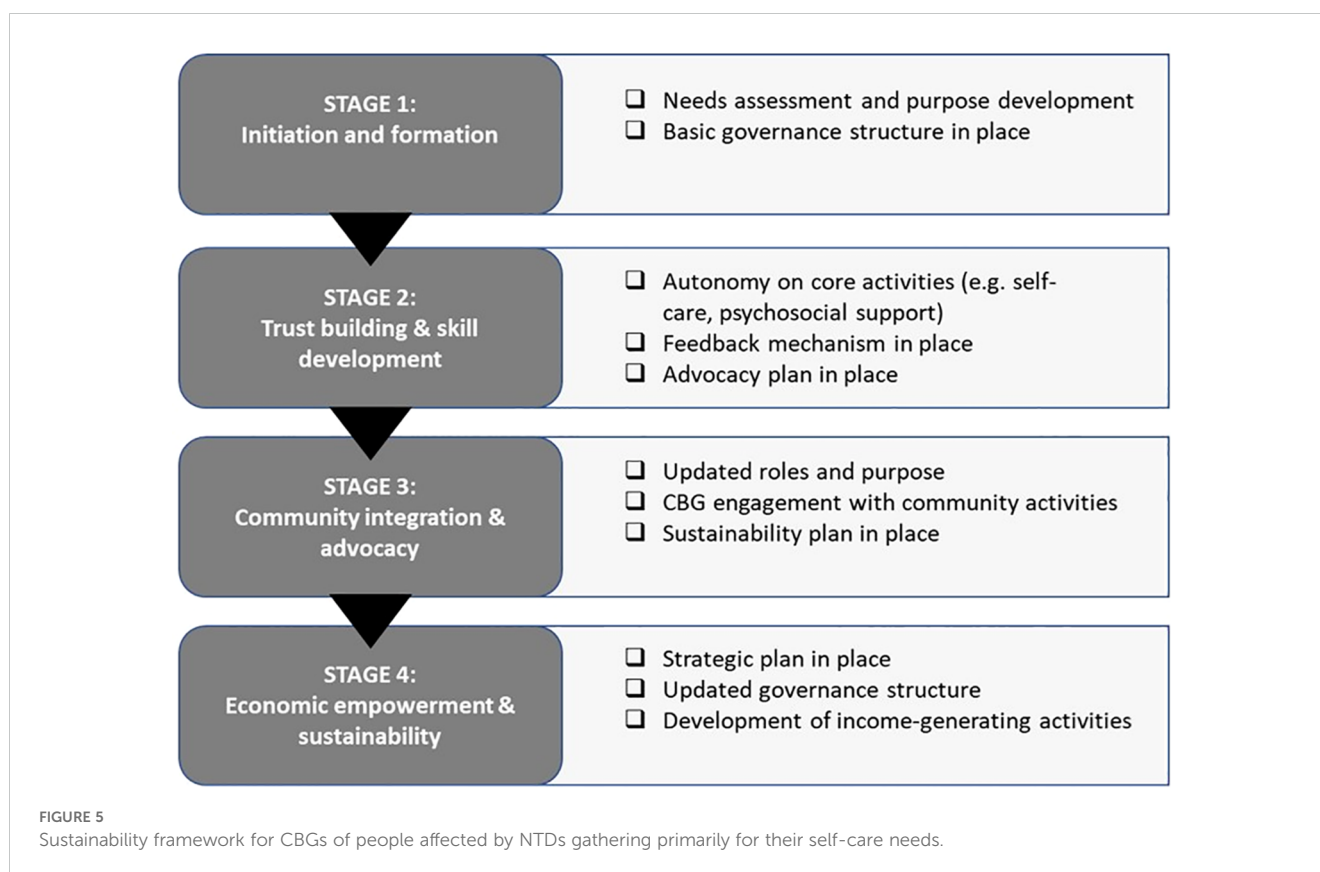
56% of the studies referred to sustainability, with some practical examples of sustainable approaches to CBGs given, for example using locally available materials, cascading training to people affected and family members and transfer of facilitator role. The WHO repeatedly emphasise the importance of sustainability throughout their road map (2). However, just under half of the studies did not mention sustainability at all, aligning with the gaps highlighted by other scoping reviews (51, 55). Moreover, even where studies did mention sustainability, none of them included outcomes related to sustainability and it was only central in a few papers (judged by whether or not it was discussed in the abstract) (23, 40, 55).

The sustainability of CBGs relies on ensuring the continuity of impact, fostering active participation of people affected and mobilising multisectoral partnerships (Bassey 39). Continuity of impact involves maintaining and expanding the positive changes initiated by CBGs. To achieve this, dependence on external facilitators must be reduced, and processes should be designed to be attainable and financially sustainable for CBG members (28). Active participation is a prerequisite to ensure CBG ownership and legitimates the formalisation of independent CBG structures that evolve to maximise impact and influence (29, 46, 47). Therefore, mobilising multisectoral partnerships and empowering CBGs to dialogue with key stakeholders, including community structures, is vital for accessing knowledge, resources and networks needed to enhance CBG capacity to achieve the group's purpose and improve their impact within the broader system (41, 61, 63).

In practice, these three concepts – continuity of impact, active participation, and multisectoral partnerships- are intrinsically linked to the empowerment of CBG members, achieved through skill development and the progressive shift in decision-making power (28, 30, 33, 36, 47, 60). After groups are formed and initial governance structures are established, external facilitators must assist members so they take ownership of their groups, moving from passive engagement to active leadership. This shift not only builds trust and fosters a sense of responsibility within CBGs, but also ensures that activities are aligned with the needs and objectives of group members, enhancing long-term commitment and sustainability.

When CBG members gather, it is crucial that they reach autonomy as soon as possible, and that other parallel core activities such as psychosocial support is led by group members in the early stages. As groups mature, activities evolve to encompass wider community and advocacy initiatives (41). At this stage, the





purpose and governance structure of CBGs may change to address the needs for such growth, shifting the focus to mid and long-term outcomes. Early planning and integrated participatory approaches such as feedback mechanisms within CBG structures are therefore crucial for successful transitions. Partnerships and networks are instrumental in integrating CBGs into the broader health and social systems, ensuring that they are supported and recognised at multiple levels (35, 41, 60, 61, 63). These also help reducing stigma and foster a more inclusive environment, where the needs of people affected are understood by the wider community and different stakeholders (24, 27, 43).

Financial sustainability is key to ensure the continuity of CBGs. Although several activities have been proposed to support this, further research is needed to better understand the factors and drivers that contribute to success. Activities such as community development, livelihoods and micro-credits schemes develop over time as the group builds skills and ownership, but they require early planning and active member participation from the beginning to be sustained in the long-term (41). Based on these findings, we propose a sustainability framework for CBGs, illustrated in Figure 5.

## 4.7 Strengths and limitations

The strengths of our study include the fact that we incorporated both peer-reviewed and grey literature, and developed and implemented a relatively broad search strategy in collaboration with a librarian. Aside from contributing to the evidence-base on

CBGs for skin-NTDs, the findings from this review have shaped international consultation workshops with professionals working on the ground on skin-NTDs and will ultimately shape the development of the UPLIFT consortium's CBG framework which will be operationalised and evaluated within Ethiopia, Bangladesh and India.

Whilst our scoping review revealed a wealth of research on CBGs, there are several limitations to consider. Firstly, our review only included studies published in English – this may have contributed to the geographical distribution of studies and potentially risked excluding valuable research from the field conducted in languages other than English. We also acknowledge the limitations due to the heterogeneity in study designs and outcomes. We chose a scoping review design, which includes all studies regardless of the quality, there was no form of evaluation; it may have been useful to examine the quality of the evidence-base beyond commenting on the types of designs. As new evidence emerges, a systematic review and or realist evaluations which consider what works for who and in what context, might be appropriate. Finally, whilst we did search for grey literature, the search could have been more comprehensive and whilst this scoping review focused only on the NTD sector, other wider disability sectors, e.g., HIV could have contributed to further insights on best practices and sustainability.

## 5 Conclusion

Community-based groups (CBGs) present a viable solution to delivering sustainable, integrated, person-centred care to people

affected by skin NTDs and achieving empowerment and active participation and ownership of people affected by skin-NTDs. Our review identifies significant gaps in current CBGs, particularly the narrow focus on leprosy, the limited research in the African region, and the lack of emphasis on mental health support, livelihoods, and advocacy and awareness activities. Furthermore, evaluative measures are inconsistent, and aspects such as integration, mainstreaming, sustainability, and gender dynamics are seldom formally addressed.

To address these challenges and work towards a harmonised CBG approach, further research must be conducted, especially in the African region, targeting multiple skin-NTDs in unison. Strategies such as presenting successful models, conducting training sessions, and organising visits to successful CBGs should also be delivered to facilitate effective scale up of CBG interventions, with support from our framework of best practice to inform programmatic design.

## Author contributions

IH: Data curation, Formal analysis, Investigation, Methodology, Project administration, Software, Validation, Visualization, Writing – original draft, Writing – review & editing. SC: Data curation, Formal analysis, Investigation, Project administration, Software, Validation, Visualization, Writing – original draft, Writing – review & editing. GR: Conceptualization, Funding acquisition, Investigation, Methodology, Project administration, Resources, Validation, Writing – original draft, Writing – review & editing. MS: Funding acquisition, Project administration, Resources, Writing – original draft, Writing – review & editing. MP: Writing – original draft, Writing – review & editing. AF: Writing – original draft, Writing – review & editing. Md: Writing – original draft, Writing – review & editing. CV: Writing – original draft, Writing – review & editing. MR: Writing – original draft, Writing – review & editing. RS: Writing – original draft, Writing – review & editing. BH: Writing – original draft, Writing – review & editing. AB: Writing – original draft, Writing – review & editing. LD: Conceptualization, Project administration, Resources, Supervision, Visualization, Writing – original draft, Writing – review & editing.

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## Conflict of interest

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

## Generative AI statement

The author(s) declare that no Generative AI was used in the creation of this manuscript.

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