A study to strengthen people centred care for people affected by skin neglected tropical diseases in Liberia

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REDRESS: Reducing the Burden of Severe Stigmatising Skin Diseases through equitable person centred approaches to health systems strengthening in Liberia (RIGHT Call Round 2)

DETAILS OF PROJECT

REDRESS is a demand-driven implementation research study led by the Liberian Ministry of Health, research and implementing partners, and people with lived experience of skin NTDs. REDRESS seeks to strengthen integrated care for people affected by NTDs using participatory action research (see pathway for communication and collaboration throughout the research process in figure 1 below).

Avenues for engagement and communication, include:

- Community advisory boards (CAB) which include representatives of people with lived experience, health workers, informal providers and County Health Teams, who play an important role in intervention development as well as raising awareness within their communities.
- Ministry of Health (MoH) technical advisory boards/ working groups ensure multi-disciplinary collaboration, for localisation of existing interventions, such as the integration of mental health within case management for people affected by skin NTDs.
- People affected by skin NTDs and other community health workers actively participate throughout all study stages via their role as co-researchers .
- People affected and other community actors, including informal providers (faith and traditional healers) are involved through participatory research methods.
- Sharing lessons learned with other NTD actors within Liberia and beyond.

Figure 1: Participatory action research process to design and integrated health systems intervention to address skin NTDs



CAB

Formative research using participatory methods



discussions



Collaborative workshops including all stakeholders



MOH technical working groups co-create tools



Sense checking of intervention tools with end users

Participatory training for 3423 health workers, CHWs, informal providers and affected persons

METHODOLOGY

We sought to understand the value of participation for CAB members and coresearchers through focus group discussions (3), reflective diaries (21) and in-depth interviews (11) across study counties in Liberia.

FINDINGS

- Participants described personal capacity building and career development.
- Affected persons described their hopes for future treatment, and for advocacy and greater awareness about the needs of affected persons.
- All participants described their ambition to help others through their role within the CAB or as a co-researcher.
- Increased cohesion between affected persons as a result of the collective process.
- There was a sense of pride in their role, the opportunity to help their community and also increase understanding about NTDs, the health system and lives of affected persons.
- Some participants described having the opportunity for influence within REDRESS and with national MoH stakeholders.

RECOMMENDATIONS

Greater opportunity for cross-county learning between CABs, job aids and identification for CAB members, ongoing capacity building and opportunity for greater innovation to raise awareness and support affected persons by CAB members.

"We will be advising REDRESS; 'o REDRESS this is what we want you people to do...This is what we want you to pay attention to ... We want you to redress it'." (Person Affected Co-Researcher, Lofa).



Photo 1: Mid term review meeting including MOH, health workers, CHWs, faith & traditional healers, CAB members, affected persons providing space for shared learning

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