Abstract for REDRESS Project 1: Exploring the value of community engagement activities within a multisectoral study to improve care for people affected by severe stigmatising skin diseases in Liberia.

Background: Severe stigmatising skin diseases (SSSDs) are a type of neglected tropical disease, that can impact physical and mental wellbeing through discrimination and stigmatisation. REDRESS multisectoral study aims to reduce the burden of SSSDs through a person-centred approach, which includes strong community engagement (CE). There is limited literature surrounding SSSDs and CE, and a narrative literature review showed a gap between idealist CE standards and their application in research processes.

Purpose: This study aims to explore the value of CE within REDRESS to reduce the burden of SSSDs. The objectives are to review CE standards within research processes, understand the value of CE through exploration of peer-researcher and dual role researcher roles, and to identify challenges and areas of opportunity for CE within REDRESS.

Methods: Eleven purposefully selected in-depth interviews were conducted in Liberia with peer-researchers and dual role participants, (Ministry of Health implementers and REDRESS researchers). Results were triangulated through secondary analysis of 21 reflexive diary transcripts conducted by the REDRESS research team. Data was analysed inductively through a thematic approach. Quality assurance steps were taken to mitigate weaknesses in my limited experience and positionality as a researcher, and findings were shared and discussed with other skilled researchers.

Findings: The study found that REDRESS CE aligned with core UNICEF CE standards. The main findings are value creation for individuals, communities, and REDRESS. Engagement activities led to capacity building and collaborations, giving communities tools to make changes and share knowledge. Engagement activities had transformative effects of improved trust and health seeking from persons affected. Participants in this study felt they influenced others, within REDRESS and in the Ministry of Health. The primary research within REDRESS identified CE activities not found in the literature review, which were the use of persons affected as peer-researchers and communities taking part in project monitoring through keeping reflexive diaries. The position of researchers within their communities benefited the project, enabling processes that wouldn't otherwise occur. However, this comes with ethical considerations surrounding consent and power dynamics. Few challenges were discussed directly related to REDRESS, but individual challenges related to dual role time management, external factors, and differences in agendas.

Implications: Activities led to empowerment, ownership, sustainability and contributed to the REDRESS goal of reducing the burden of SSSDs. The study found CE activities to be at the higher end of the community engagement continuum, where communities form partnerships, make decisions which lead to broader health effects. Opportunities for improvement have been identified, and recommendations to strengthen CE include capacity building, clearer communication and addressing power imbalances.

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