

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

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Introduction:

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. This study aims to explore the value of CE within REDRESS to reduce the burden of SSSDs.



Figure 1: Representation of SSSDs focused on by REDRESS that are endemic to Liberia, taken online from REDRESS (2021)

Method:

- Study design: Narrative literature review and primary qualitative study (naturalistic paradigm)
- Eleven purposefully selected in-depth interviews were conducted in Liberia (Figure 2) with PA (persons affected) peer-researchers and dual role participants, acting as



Figure 2: Map of Liberia with study sites circled.

- Ministry of Health (MOH) implementers and REDRESS researchers.
- Results were triangulated through secondary analysis of 21 reflexive diary transcripts conducted by the REDRESS research team. (Figure 3)

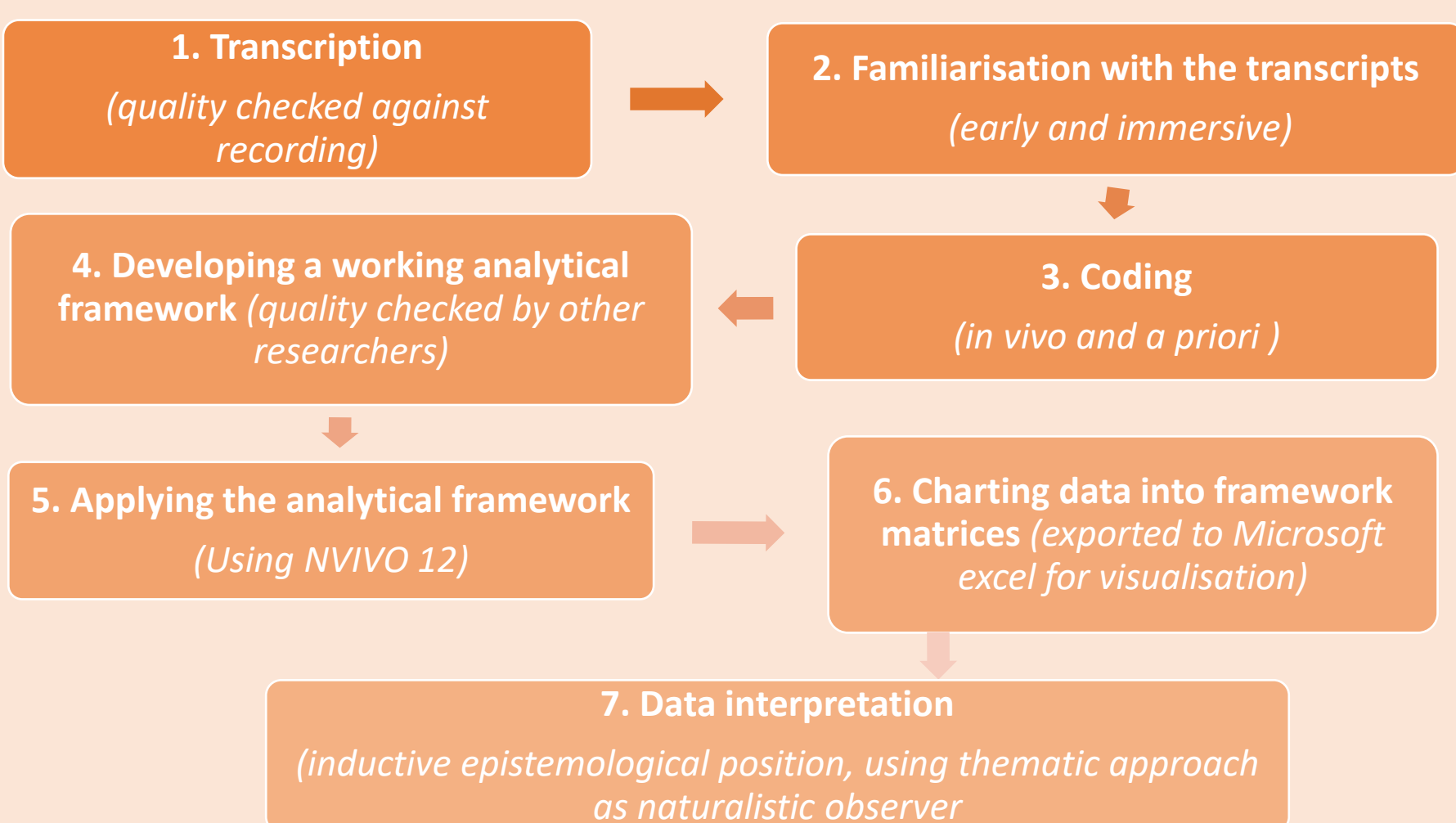


Figure 3: Data management steps interpreted from Gale et al (2013)

Results:

Value - relating to perceived future:

- All wanted **personal gains** by capacity building, career development or resources (one PA wanted treatment and a Co-R finances) as well as an **ambition to help others**.

Value - relating to past experiences:

- **Capacity building** most said, in communication skills, publishing opportunities, academic skills, technology (rural), knowledge in research and NTDs (and how to share it)
- **Revelations** in travel, own culture (faith and traditional healers), exposure to health system and burden of NTDs (prevalence, health seeking behaviour and stigmatisation)

Value of past interactions:

- **Collaborations:** with researchers, institutions, healers and leaders
- **Relationships with PA:** positive impact on health seeking through encouragement. *"they become family"* (Dual Role Co-R, Lofa)

Felt transformative change:

- **In personal activities:** counselling, encouraging others "to get on their feet" and refer cases, lifestyle changes, keeping reflexive diaries.
- **Change in mentality:** new future aspirations, a change of understanding of community needs and ability to influence care. *"REDRESS have motivated me to take that path."* (PA Co-R, Lofa). *"...it made you to know community ... to know people's problem"* (Dual Role Co-R, Margibi)
- **Improvement in trust and health seeking behaviour:** due to communication and education and PA acting as evidence that diseases can be cured.

Participant position in research:

- **Shaped their role in REDRESS:** prior knowledge, similarity in activities, national input on project implementation and speaking local dialects.
- **Influence in REDRESS:** giving suggestion (MOH), material control and community advisory board (PA) *"Redress is up there and we are down here, we see more things in the field and they are supporting us"* (Dual Role Co-R, Lofa).
- **Advocacy with MOH:** national level felt they could push for changes at meetings.
- **Influence on others:** most, by encouraging PA to seek treatment. Influence seen as positive and lasting thing.
- **Ethical considerations:** hesitant topic, dual roles did not feel they influenced consent process (only encouraged). Mixed view on facility level influence (county dual roles worked in different counties).

Creating an enabling environment:

- **Individual challenges:** time management and workload (national level), logistical problems (county level), working with health representatives (one PA).
- **REDRESS challenges:** mentioned by one national MOH IDI related to over-adjusting project objectives, and the use of different data collection tools.

Implications:

Activities led to empowerment, ownership, sustainability and contributed to the REDRESS goal of reducing the burden of SSSDs. The study found that REDRESS CE aligned with core UNICEF CE standards (Table 1). Activities were at the higher end of the community engagement continuum, where communities form partnerships, make decisions which lead to broader health effects.

Opportunities for improvement:

1. Improve cascade training of research activities
2. Clearly define roles
3. Honest and transparent communication
4. Acknowledge and address power
5. Listening to researcher's concerns

REDRESS is seeking to consider these recommendations as it continues implement interventions for health workers, informal providers and persons affected to support health and wellbeing for people affected by SSSDs. See the manual here: <https://www.redressliberia.org/resources/>

Table 1: UNICEF (2020) community engagement standards against REDRESS engagement examples found in study

Standard	The examples shown in study
Participation	Activities involved national MOH, county MOH, person affected, faith and traditional healers.
Empowerment and ownership	Nationals involved in decision making, co-researchers felt they could influence others.
Inclusion	Persons affected acting as data collectors and activity participants
Two-way communication	Feedback processes are in place at the national and county level
Adaptability and localisation	Formative baseline research to assess needs, modification to the program from findings. the use of locals to collect data.
Building on local capacity	Training in research and NTDs at the national, county and community level

References:

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Acknowledgements: Thank you to Dr Rosalind McCollum, Dr Laura Dean, Zeela Zaizay and the rest of the REDRESS research team for their support and guidance and for making this project possible. My sincere thanks to all participants for taking their valuable time to talk to me, and to the British Dermatology Association for providing a project grant.