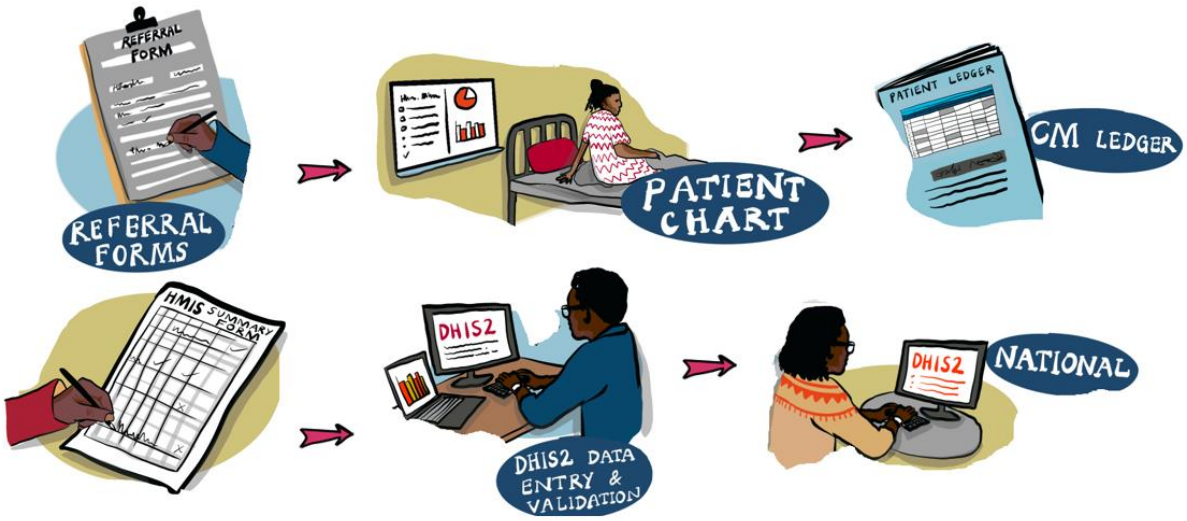
REDRESS

Reducing the burden of
Severe Stigmatising Skin Diseases

New data collection tools, training and supervisions produce reliable data, enabling effective decision-making and improved diagnosis, care and outcomes for persons affected by skin NTDs



Summary

- The availability of timely, reliable data is crucial in producing evidence on the integrated skin NTD programme implemented by REDRESS as well as contributing to the WHO's 2030 skin NTD targets.
- Formative research illustrated a convoluted data pathway with numerous errors relating to record keeping, NTD ledgers and discrepancies between ledgers and HMIS data, resulting in unreliable skin NTD data.
- Through implementing training and supervisions, engaging stakeholders and introducing a new integrated clinical ledger which includes mental health indicators and skin NTDs previously missing, the intervention has improved record keeping and ledger use, producing timely reliable data which is enabling informed decision-making and advocacy, ultimately improving patient diagnosis, care, and outcomes.

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Background

Why is data management important for effective case management?

Effective case management of NTDs requires data; without reliable data, it is challenging to identify and prioritise conditions, geographical areas and health facilities that require intervention. Moreover, the availability of timely, reliable data is essential in making informed decisions and allocating resources, such as drugs and diagnostic tools, effectively across all levels, playing an integral role in the supply chain (see supply chain case study). Additionally, data plays a vital role in monitoring and evaluation of the progress of NTD control programs and evaluating their impact, enabling transparent, responsive programming. Crucially, collecting disaggregated data aligned with WHO indicators is integral to all three of the WHO's pillars for meeting the elimination 2030 targets of accelerating programmatic action, intensifying cross-cutting approaches and increasing country ownership.

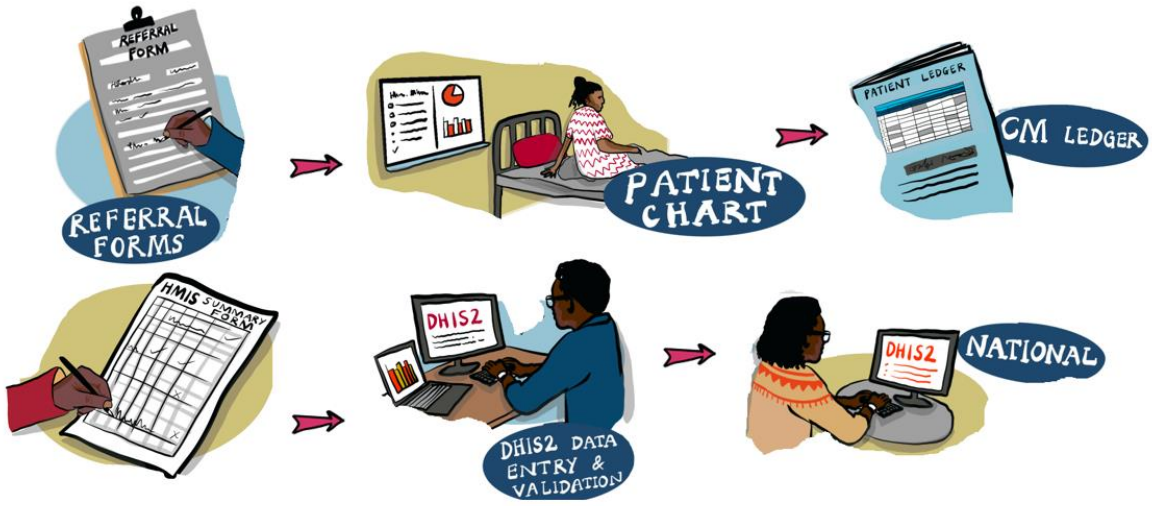

Figure 1. Flow of NTD data in Liberia

REDRESS formative research mapped out the flow of NTD data in Liberia; as figure 1 illustrates, data is collected via referral forms and patient charts, which is aggregated on a monthly basis via the integrated ledger at the health facility level, which is then submitted to the county data management via the HMIS. Next, data is entered and validated using the DHIS2, before being reported to the NTD national programme. If there is a notifiable case, data is passed on to the WHO.

> ***"Health facility will report and time comes, we see it in on the HMIS form or in the DHIS tools, because several times I go on the field. Sometimes, I would take some photos, people that reported, but when I come in the… on the county level to check, you will see that it's not there."***
>
> County Health Worker, Margibi County

Throughout REDRESS, challenges were also identified along the data pathway, with a lack of accuracy and up-to-date data becoming apparent in some settings. Specifically:

- Ledgers did not include all NTD conditions or mental health indicators.
- Data collected in ledgers was not accurately transmitted to counties via aggregated reports and there was generally limited ledger availability and use within facilities
- Data entry at the health facility level had multiple types of error due to poor record keeping e.g., missing important information, repeated patients, use of general ledger instead of NTD ledger, etc.
- Data quality of HMIS was heterogeneous - some values (especially peaks in cases) did not correspond to the reality.
- Mismatch between ledgers and HMIS data (about 45% more observations in ledgers than HMIS data in 2022/2023) (see figure 2).

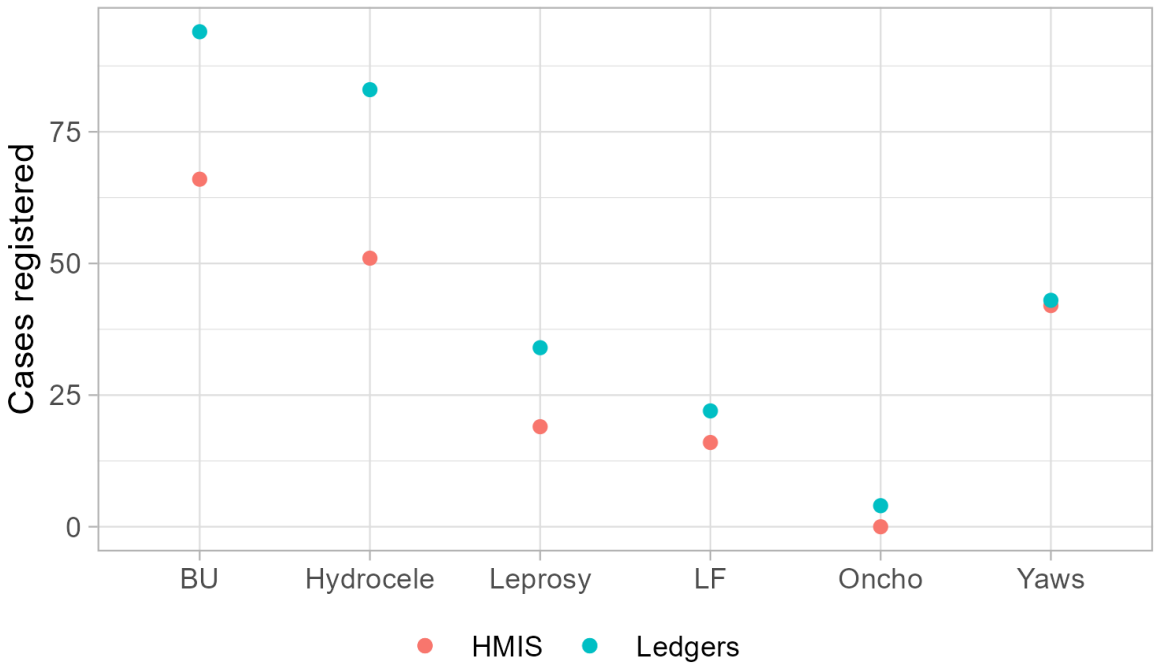

Figure 2. NTD cases registered in the HMIS and ledgers in 2022/2023 across selected health facilities (n=81) in Grand Gedeh, Lofa and Margibi counties. Source: HMIS and primary data collection

What was the impact?

Healthcare actors have a renewed appreciation for the importance of collecting good quality data and have developed data management skills through training and supportive supervision, with data validation now conducted at the health facility level.

The new, user-friendly integrated ledger is more accessible and being used widely (see our intervention manual to view the ledger).

Improvements in data quality have been achieved through the national team becoming responsive to data issues and routinely checking data from the county and district levels.

> ***"Now when we come to the clinic, in the NTD ledger we can check now and find cases that the clinician… they are sitting there and we checked the charts also you can find those cases them there, but before to find case or even self-see things in the ledger, it can be hard. For now, we are seeing case, we seeing, we the data people that the case we can make out of figures so we are getting now on the server."***
>
> District Health Worker, Grand Gedeh County

The inclusion of mental health tracking and onchocerciasis in the ledgers provided invaluable data to help identify needs and gaps in those areas. Having accurate mental health data for the first time provided visibility into this critical issue and is facilitating access to mental health care for persons affected and supporting advocacy efforts.

Improvements in ledger use and data quality are having significant positive impacts. As illustrated in the chart, there was a significant increase in data concordance between the ledgers and HMIS starting in mid-2023 when the interventions were implemented. By December 2023, the concordance rate reached over 90%, indicating the discrepancies between the two systems were largely resolved.

Improvements in data quality are enabling better decision making and resource allocation by health authorities across all levels. With more accurate disease burden data across conditions, geographic regions, and facilities, limited resources can now be effectively targeted to areas with the greatest need.

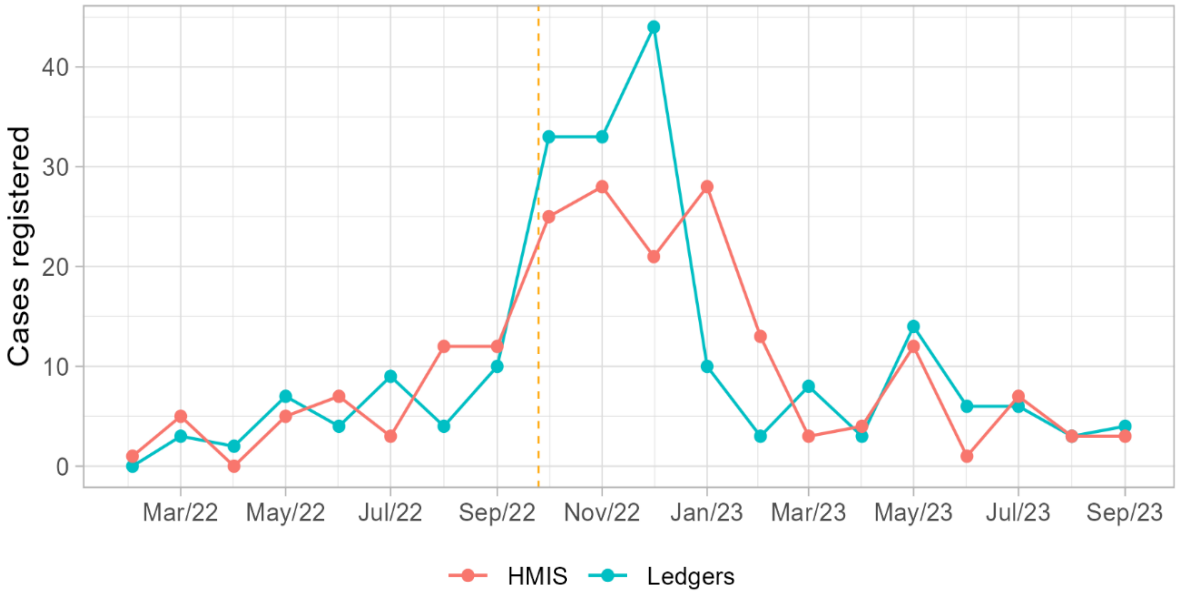

Figure 3. Monthly cases registered in the HMIS and ledger in 2022/2023 in selected health facilities (n=81) in Grand Gedeh, Lofa and Margibi counties. Source: HMIS and primary data collection

While some data quality challenges remain, the new integrated ledger system and focus on data accuracy have led to more reliable, comprehensive data to drive NTD programming and evaluation nationally. This will ultimately help improve patient diagnosis, care, and outcomes.

Ongoing training and ledger expansion efforts aim to build on this progress and ensure continuous data quality improvements into the future.

How did REDRESS address data management issues?

REDRESS took a multi-pronged approach to improving NTD data collection, quality, and integration:

- **Developed a new standardized integrated clinical ledger:** for use across facilities to replace older ledgers. The new ledger captures comprehensive information on patient visits including mental health metrics (PHQ-9, GAD-7) and onchocerciasis tracking which were previously excluded.
- **Conducted in-depth analyses of data flow bottlenecks:** including assessing the ledger use, data extraction and transmission processes to identify quality issues, especially at the initial health facility level.
- **Implemented robust data validation, auditing and correction mechanisms at the HMIS level:** to improve reporting accuracy, through identifying anomalous aggregate values and working to correct errors.
- **Quantified and evaluated the mismatch between ledger and HMIS reported cases:** doing so helped facilitate data comparisons and improvements.
- **Provided extensive training to over 200 healthcare workers and county officials:** on proper use of the new integrated ledgers as well as accurate data collection and reporting processes. Training emphasized complete, accurate, and timely reporting (see training case study).
- **Supported initial rollout of integrated ledgers in over 150 public healthcare facilities in priority regions:** ledger use will continue to be expanded nationally.
- **Engaged county and national NTD program managers in the data improvement process:** helped ensure buy-in and accountability.

Through this intensive, collaborative process spanning staff training, new tools, analysis, validation and stakeholder engagement, REDRESS tackled the complex web of challenges undermining data utility. The resulting improvements in concordance, accuracy and completeness provide for superior NTD surveillance, decision-making and resource deployment.

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References

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