

# Strengthening Data Security Policies and Practices in Neglected Tropical Disease Programs

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## INTRODUCTION

Neglected tropical diseases (NTDs) are a diverse set of 20 diseases and disease groups with a singular commonality: their devastating and disproportionate impact on impoverished communities. Untreated, NTDs can lead to life-altering disabilities that prevent patients from working, attending school, and gaining socioeconomic mobility to name a few. Great strides have been made to eliminate and control the spread of preventative chemotherapy diseases such as onchocerciasis, trachoma, schistosomiasis, soil-transmitted helminths, and lymphatic filariasis through donor- and community-led mass drug administration (MDA) campaigns and government action.

As countries move towards national goals and targets, the need for reliable data management and secure data systems are required for the preparation of elimination dossiers, drug applications, and to inform programming. While governments across West and Central Africa are adopting national data strategies, Ministries of Health (MOH) often do not have formal data security policies in place to secure the protected health information of their patients. For national NTD Programs (NTDPs), data are often stored on unsecure Excel sheets or on personal devices of health staff. NTDPs have acknowledged the need to standardize how programmatic data are stored to ensure data integrity, analysis, and security, and to facilitate knowledge transfer between staff, assure the validation of their data, and protect data from possible inaccuracies and loss. Supporting NTDPs across eleven West and Central African countries, USAID’s Act to End NTDs | West (Act | West) program created a four-phase methodology to aid countries in ensuring accurate, protected data are readily available to propel analysis and data-driven decision-making for NTD service delivery.



Countries supported by USAID’s Act to End NTDs | West

## APPROACH & RESULTS

Act | West supports the NTDPs in evaluating data security policies using leading global references such as the U.S. National Institute of Standards and Technology (NIST) Framework for Improving Critical Infrastructure Cybersecurity and USAID’s Digital Strategy for 2020-2024. The NIST Framework breaks down data security into five (5) categories:



Figure 1. NIST Cybersecurity Framework

The NIST Framework provides the basis for Act | West’s four-phase approach developed to support NTDPs to improve data security policies, illustrated below in Figure 2. At the forefront of this approach are facilitating collaboration and encouraging ownership of this process by relevant stakeholders from all levels of the health system such as community drug distributors, regional health data managers, and NTDP directors. This is reflected from the initial stages of research and analysis of data security current practices to the national level workshop in Phase 3.

Examples of concrete data security procedures to adopt include: fully integrating NTD data entry and storage into existing national health information platforms; establishing clear roles and responsibilities for the protection of physical and digital data and investigation of lost/falsified data; installing firewalls and antivirus software and acquiring centralized storage servers; improving and expanding data management trainings to more data management staff; clearer guidelines on securing data storage; and identifying various software to invest in and adapt for NTDP data collection purposes, e.g., District Health Information System 2, Epi Info, SPSS Statistics, Open Data Kit (ODK), PowerBI, Evernote, and RedCap. In drafting these policies, participants consider the level of effort, resources (e.g., human, financial), and stakeholders required for effective implementation. This process also allows NTDPs to map out, in detail, the flow of data from the point of collection during community MDA campaigns to reporting to influence national-level decision-making.

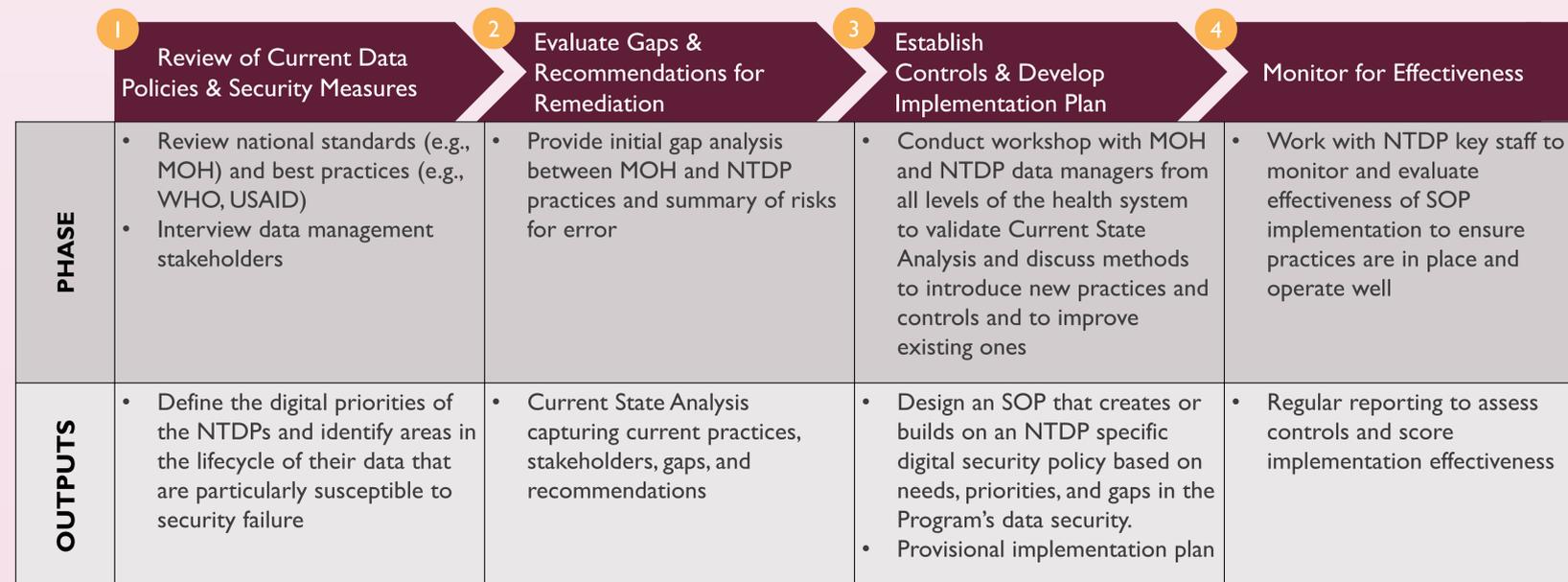


Figure 2. Act | West 4-Phase Methodology for Data Security Policy

## CONCLUSION

To date, Benin, Cameroon, and Togo have developed and begun adopting data security policy SOPs that will improve the data security of their respective NTDPs. Six other countries supported by Act | West are on track to complete respective SOPs through 2022 and 2023. Act | West will continue to monitor the progress of SOP implementation and work with country teams to continually adapt procedures specific to NTDP needs. Notably, the in-country workshops have increased synergy between the MOH and the NTDPs who worked closely together to find ways to better integrate the NTDP’s data into the national healthcare systems and databases for additional security.

As more countries push for increased digitalization and data-driven solutions, the creation, documentation, and implementation of data security policies are essential. This will help ensure that programmatic and health system data are secure and reliable, supporting health system resilience and sustainable health programming.



Data Security Policy Workshop in Yaoundé, Cameroon

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