ASSESSING THE CAPACITY OF THE HEALTH CARE SYSTEM TO HANDLE NEGLECTED TROPICAL DISEASES IN A REFUGEE SETTLEMENT IN UGANDA

PROTOCOL SUMMARY

Neglected tropical diseases (NTDs) currently affect over 1 billion people [1-8]. They strike the world's poorest people, lowering their quality of life. [9]. Over 40 million Ugandans are at risk of NTDs [13]. Despite efforts by the WHO for Universal Health Coverage, integration of NTDs into primary healthcare systems in refugee settings is unknown. This research project explores this phenomenon by assessing the capacity of facilities to diagnose and manage NTDs. We assess the health workers' knowledge of NTDs and, the availability of diagnostic tools and medication in Nakivale Settlement, Uganda. Results from this study will help inform policy and develop better interventions to curb NTDs.

BACKGROUND

Neglected tropical diseases (NTDs) are a group of 13 infections caused by parasitic worms, protozoa, or bacteria currently affecting over 1 billion people with another 1 billion at risk of infection [1-8]. NTDs. They strike the world's poorest people with adverse effects on the health, well-being, and socioeconomic facets of one's life [2, 9-11]. Africa is disproportionately affected, accounting for over 600 million of the global burden, and especially rural poor communities [1-2, 12]. Uganda is endemic for all five NTDs targeted by USAID's Act to End NTDs with more than 40 million people at risk for one or more NTDs [13].NTDs are preventable and can be eliminated. In 2020, the World Health Organization (WHO) set a roadmap for eradication and elimination of the 20 NTDs by 2030 [14]. The WHO, policymakers, and academics have also suggested that endemic countries should integrate NTD management into well-established public health programmes which can help achieve several of the Sustainable Development Goals (SDGs) and vice versa [14-16]. Despite the burden of NTDs in Sub-Saharan Africa, NTDs have not been well integrated into the PHC of most countries. Studies in Nigeria, Tanzania, and Burundi reported that health workers had low capacity and readiness to diagnose and manage NTDs [1, 17-18]. Refugee settlements despite standard minimum requirements lack NTD eradication programs within the early stage of resettlement which leads to ongoing NTD transmission within the community and even the introduction of new NTDS [19]. Refugees face significant health vulnerabilities that can intensify the prevalence of neglected tropical diseases (NTDs). For instance, overcrowded living spaces and poor sanitation in refugee camps facilitate the spread of diseases such as leishmaniasis and schistosomiasis, as these conditions support the propagation of vectors and parasites associated with NTDs [20-21], Furthermore, barriers to accessing healthcare—stemming from logistical, legal, and language challenges—hinder timely medical intervention, amplifying the burden of NTDs in these populations

[22]. Nakivale Refugee Settlement is the 8th largest settlement in the world hosting ten different nationalities of refugees amounting to about 145,613. [19]. NTDs especially schistosomiasis and Soil-Transmitted Helminths at 26.6% and 26.5% respectively are worsened by problems of rising numbers coupled with inadequate resources pausing a question of whether the available health system is capable of ably diagnosing, managing, and treating some of these NTDs [23]. There is also an inadequacy of data on NTDs and their prevalence in areas like South Western Uganda. Currently, the country's approach to NTDs entails the use of integrated control programs [24]. The Ministry of Health has cited the lack of knowledge, skills, and equipment to diagnose and manage NTDs in health facilities as well as the poor reporting systems as hindrances to the elimination of the diseases by 2030 [23]. Exploring the readiness and capability of PHC facilities to diagnose and manage NTDs is important as it will provide a baseline on which progress can be tracked. This study will assess the readiness and capacity of PHC centers to diagnose and manage soil-transmitted helminths and schistosomiasis. Results will inform and guide policy enactment and health care service provision in refugee settings hence facilitating the integration of NTDs in PHC which will accelerate the realization of SDG 3.

MAIN OBJECTIVE

To assess the capacity of primary healthcare centers to timely diagnose, treat, and manage soil-transmitted helminths and schistosomiasis among refugees in Nakivale Refugee Settlement, South Western Uganda.

SPECIFIC OBJECTIVES

To assess the knowledge of health workers on soil-transmitted helminths and schistosomiasis in Nakivale Refugee Settlement, South Western Uganda

To assess the availability of diagnostic tools, diagnostic equipment, and medications for soil-transmitted helminths and schistosomiasis in Nakivale Refugee Settlement, South Western Uganda

To analyze the facilitators and barriers to diagnosing and successfully managing schistosomiasis and soil-transmitted helminths in refugee populations in Nakivale Settlement Uganda.

METHODOLOGY

Study design

This will be a cross-sectional mixed methods study employing both qualitative and quantitative methods. A survey tool will be administered in focused group discussions and key informant interviews amongst the different healthcare provider cadres in the Nakivale Refugee settlement.

Theoretical Framework

The framework for this study is based on health systems strengthening and capacity-building principles for addressing neglected tropical diseases (NTDs), such as soil-transmitted helminths and schistosomiasis, in low-resource settings. Studies highlight the importance of integrating NTD interventions within primary healthcare to build resilience and enhance treatment efficiency [24-25]. Training healthcare personnel to accurately diagnose and manage NTDs is crucial in strengthening healthcare delivery. Community health workers play an essential role in NTD prevention, bridging gaps between formal health systems and underserved populations [26]. Capacity-building workshops focused on diagnostic skills and NTD management are recommended to ensure healthcare providers are equipped to deliver comprehensive care, supported by guidance from platforms like Open WHO, which offers training for frontline health workers [13]. This theoretical foundation supports the study's objective of improving health system capacity to meet the WHO's NTD elimination goals by 2030.

Study Setting

The study will be conducted in health facilities within the Nakivale Refugee settlement located 200 km from Kampala. The settlement is located in the Southwestern part of Uganda, Isingiro district accommodating about 150,000 people being served by two Health Centre IV facilities and six Health Centre III facilities.

Study Period

Data collection for this study will take place over two months, starting in April 2025 and concluding in May 2025. During this period, both quantitative data (from the self-reported questionnaires) and qualitative data (from in-depth interviews) will be gathered. The review and analysis of all collected data will then be conducted in June 2025 to ensure timely completion and to prepare findings for reporting to key stakeholders, including healthcare providers and policy advisors involved in NTD control efforts.

Study participants

Health workers including doctors, Clinical Officers, and Nurses involved in the diagnosis and management of refugees in Health Facilities in Nakivale Settlement.

Sampling Framework

The sampling framework for this study incorporates both quantitative and qualitative methods to explore health workers' capacity regarding Neglected Tropical Diseases (NTDs). Random sampling will be employed to select health workers from primary healthcare facilities, ensuring a representative sample through direct contact and informed consent. In contrast, purposive sampling will be used for in-depth interviews, focusing on specific participants who can provide valuable insights, with arrangements made through telephone or email communication

Eligibility Criteria

Inclusion criteria

Consented Health workers in health centers III, IV, and district hospitals involved in the diagnosis and management of refugees

Exclusion criteria

Health workers who have not been engaging in the diagnosis or management of NTDs

Sample size estimation

The sample size of 128 participants was determined using a Select Statistical Services online tool (Select Statistical Services, 2022) that uses the formula $n = N*X / (X + N - 1)$, where, $X = Z_{\alpha/2}^2 *p*(1-p) / MOE^2$, and $Z_{\alpha/2}$ is the critical value of the Normal distribution at $\alpha/2$ (e.g. for a confidence level of 95%, α is 0.05 and the critical value is 1.96), MOE is the margin of error, p is the sample proportion, and N is the population size. Finite Population Correction was applied to the sample size formula. A 10% non-response rate was factored in to have a total sample size of 141 participants.

The sample size of in-depth interviews will be driven by thematic saturation rather than statistical power. Previously published empirical investigations suggest that we can expect to achieve thematic saturation with 12-16 in-depth interviews [27-28] although some guidelines suggest conducting no fewer than 30 in-depth interviews [29]. We hope to conduct between 12-25 in-depth interviews.

Data collection

This study will be conducted amongst health workers in PHC facilities and obtained by random sampling. Participants will be contacted, consented, and enrolled in the study.

Participants for the in-depth interviews will be obtained using purposive sampling and contacted through a telephone call or email for the in-depth interviews to be informed of the purpose of the study, consent and their anonymity maintained as they schedule the best time for the in-depth interview. These interviews will be conducted over the Zoom Meeting platform lasting between 30 and 45 minutes. The meeting will be audio-recorded and moderated by two research assistants, one asking the guiding questions and the other taking notes. Research assistants will be trained by the study investigator to pretest the data collection tool.

Data Management and Analysis

Data Collection and Logging: All raw data from surveys, interviews, and case reports will be systematically recorded in an Excel spreadsheet. This will facilitate both data storage and progress tracking for each phase of data collection. To enable comprehensive analysis, interview transcripts will be converted to text files and prepared for in-depth analysis using STATA 17.0 (Stata Corp, College Station, Texas, USA) for quantitative data and atlas.ti® for qualitative insights.

Data Collection Tools:

1. **Self-Reported Questionnaire:**

A self-reported questionnaire, adapted and modified from resources on the Open WHO platform dedicated to Neglected Tropical Diseases (NTDs), will be used to collect data from participants. This questionnaire will gather essential information on:

- Sociodemographic Characteristics: This includes data such as sex, marital status, type of health facility, and cadre of health personnel.
- Knowledge of NTDs: Questions will assess participants' knowledge about the symptoms, diagnosis, treatment, and complications related to soil-transmitted helminths and schistosomiasis.
- Case Reports: Data on recorded cases, if any, will be collected to provide insights into the prevalence and management of NTDs within the study setting.

2. **Interview Guide for In-Depth Interviews (IDIs):**

An interview guide will be developed specifically for conducting in-depth interviews. This guide will focus on qualitative aspects to gather detailed insights, particularly on:

- Capacity Building for Health Personnel: Information on ongoing training, skills development, and readiness of healthcare workers to handle NTD cases.
- Availability of Diagnostic Tools and Medicines: Questions will cover the availability, accessibility, and adequacy of diagnostic tools and essential medicines used to manage NTDs, as well as any challenges related to supply and logistics.

Quality Control: Interviewers will undergo extensive training in effective qualitative data collection techniques, focusing on creating a comfortable, open atmosphere that encourages honest responses. Basic facilitation skills will also be taught to enhance focus group discussions (FGDs). Peer debriefings will be conducted after each session to review and improve the data collection process, ensuring accuracy and consistency in capturing participants' responses.

Data Triangulation: Data triangulation will be applied to validate findings by comparing results from FGDs and in-depth interviews (IDIs). After each session, preliminary findings will be shared with participants to ensure accuracy and completeness, adding rigor and credibility to the study's outcomes.

Data Archiving: All raw data will be organized into structured archives to create a reliable audit trail, allowing for verification and reproducibility of results. This archive will support future analysis by serving as a benchmark to confirm the consistency of interpretations with the initial findings.

Data Analysis:

- **Quantitative Data:** Completed questionnaires will be logged into Microsoft Excel 2016 for cleaning and coding before being exported to STATA 17.0 for comprehensive analysis. Categorical variables will be summarized with frequencies and percentages, while continuous variables will be presented as means (standard deviation) or medians (interquartile range) based on data distribution. Associations among independent variables will be tested using chi-square or Fisher's exact test for bivariate analysis. Variables with a p-value <0.2 will be included in multivariable logistic regression to adjust for potential confounders. Results with p-values below 0.05 will be considered statistically significant and presented through tables, charts, and graphs for clarity.
- **Qualitative Data:** Data from IDIs will be transcribed and anonymized before being imported into atlas.ti® for thematic analysis. Themes will be organized according to the research questions and findings from existing literature, focusing on areas such as knowledge of NTD symptoms, treatment, and healthcare access. The systematic coding of qualitative data will help identify key thematic domains and ensure findings are relevant to both the research objectives and contextual insights.

Ethics and Confidentiality: Ethical approval for this study, which assesses knowledge, attitudes, and practices (KAP) regarding NTDs, will be sought from the Lacor Hospital Research Ethics Committee and the Uganda National Council of Science and Technology (UNCST). Participants will be informed of the study's purpose, and consent will be obtained, emphasizing that participation is voluntary and will not affect any benefits they might receive in the future. An introductory session or written letter will outline confidentiality measures, ensuring participants' anonymity and data privacy.

Informed Consent Process: Prospective interviewees will be approached by recruiters who will provide detailed information about the purpose and procedures of the entire needs assessment process. It will be emphasized that refusal to participate will not impact any future benefits they may be entitled to receive.

Introduction to the Study: Each interviewee will receive an introduction to the study, either through a talk or a written letter, outlining the discussion's nature, expected duration, assurances of anonymity, and confidentiality. No personal identifiers, such as names, were collected during data collection to ensure the privacy and confidentiality of participants' responses.

Community Engagement Plan: The community will be stratified for focus group discussions based on factors like delivery mode in maternal studies and NTD risk factors in health workers. Separate FGDs will be held to address the specific needs and challenges of each group, enhancing relevance to their unique experiences. Participants will be informed of the study's purpose to guide improvements in NTD healthcare in low-resource settings like Nakivale Refugee Settlement.

Data Security: All recorded data, including transcripts and field notes, will be stored in secure, locked cabinets and electronically in password-protected files. Access will be restricted to essential research team members, with the highest standards of confidentiality maintained throughout the study.

Access to Raw Data: Access to raw data from the needs assessment will be limited to the research team and will be stored electronically on the lead investigator's computer with robust password protection. However, the Lacor Hospital Research Ethics Committee may be granted access to the data when necessary.

Confidentiality Assurance: Participants will be explicitly informed that the results obtained from this needs assessment will be used for research purposes and for developing interventions aimed at improving NTD Care. No personal identification information will be collected. The highest standards of confidentiality will be maintained throughout the study to protect the privacy and dignity of all participants.

Risks and Mitigations:

- **Participant Discomfort:** Participants discussing NTD-related experiences may experience psychological discomfort. To address this, confidentiality assurances will be provided, and a trained counselor will be available to offer support.
- **Interviewer Fatigue and Bias:** Interviewers may experience fatigue or unintentional bias during data collection. Standby interviewers will be prepared to ensure consistent quality. Reflexive practices will be encouraged, helping interviewers remain aware of personal biases that may influence their data collection or analysis.

Primary Outcomes:

- **Assessment of Health Worker Capacity:** Evaluate the capacity of healthcare workers to accurately diagnose, treat, and manage NTDs, identifying specific gaps in skills or resources.

- **Capacity-Building Recommendations:** Develop insights to inform capacity-building initiatives, including potential workshops or training for healthcare workers on NTDs to strengthen diagnostic and treatment capabilities.

Secondary Outcomes:

- **Stakeholder Engagement and Reporting:** Prepare a comprehensive report for stakeholders in NTD prevention and control in Uganda, including the UNHCR, to support strategic efforts toward the 2030 NTD elimination goals.
- **Publication for Knowledge Sharing:** Publish the study findings in a peer-reviewed journal to contribute to scientific knowledge and allow for replication of effective methods in other resource-limited settings.
- **Benchmarking for Future Developments:** Utilize the findings as a benchmark for future improvements, particularly in designing targeted training sessions and workshops focused on addressing identified needs in NTD management among health workers.

Dissemination:

- **Utilization of Findings:** The study findings will contribute empirical evidence to improve NTD healthcare services in Uganda and other resource-limited settings. Findings will also be shared with key stakeholders through comprehensive reports, conferences, and peer-reviewed publications.
- **Peer-Reviewed Publication:** To ensure knowledge sharing and facilitate replication, the study will be submitted for publication in a peer-reviewed journal, contributing to global health literature on NTD care in displaced populations and low-resource environments.

WORK PLAN

Commented [1]: Adjust to align with the current funding months

	RESPONSIBILITY	DEC 2024	JAN 2025	FEB 2025	MAR 2025	APR 2025	MAY 2025	JUN 2025	JUL 2025	AUG 2025	SEPT 2025
MILESTONE 1											
PROPOSAL APPROVAL	SUPERVISOR										
IRB SUBMISSION AND APPROVAL	TEAM LEADER										
MILESTONE 2											
DATA COLLECTION	TEAM MEMBERS										
MILESTONE 3											
DATA ANALYSIS	SUPERVISOR+ TEAM MEMBERS										
MILESTONE 4											
REPORT WRITING	TEAM MEMBERS										

ACCOUNTING	TEAM MEMBERS										
MILESTONE 5											
PUBLISHING	TEAM MEMBERS										
DISSEMINATIO N											

REFERENCES

1. Emeto, D. C. et al. (2021) 'Recognition and reporting of neglected tropical diseases by primary health care workers in ibadan, nigeria', Pan African Medical Journal, 38. doi: 10.11604/pamj.2021.38.224.20576.
2. Molyneux DH, Savioli L, Engels D. Neglected tropical diseases: progress towards addressing the chronic pandemic. Lancet. 2017 Jan 21;389(10066):312-325. doi: 10.1016/S0140-6736(16)30171-4. Epub 2016 Sep 14. PMID: 27639954.
3. Ochola, E. A., Elliott, S. J. and Karanja, D. M. S. (2021) 'The Impact of Neglected Tropical Diseases (NTDs) on Women's Health and Wellbeing in Sub-Saharan Africa (SSA): A Case Study of Kenya', Public Health, 18, p. 2180. doi: 10.3390/ijerph18042180.
4. Ojja, S. et al. (2018) 'Prevalence, intensity and factors associated with soil-transmitted helminths infections among preschool-age children in Hoima district, rural western Uganda', BMC Infectious Diseases, 18(1), pp. 1–12. doi: 10.1186/S12879-018-3289-0/FIGURES/3.
5. World Health Organization (WHO). Integrating Neglected Tropical Diseases into Global Health and Development: Fourth WHO Report on Neglected Tropical Diseases., 2017.
6. World Health Organization (WHO) (2017) Integrating neglected tropical diseases into global health and development: fourth WHO report on neglected tropical diseases., World Health Organization. Available at: https://unitingtocombatntds.org/wp-content/%0Auploads/2017/11/4th_who_ntd_report.pdf
7. WHO. Implementation tools Package of Essential Non-communicable disease interventions. Geneva World Health Organ 2013:210.
8. World Health Organization (WHO) (2015) 'Investing to overcome the global impact of neglected tropical diseases'.
9. Jan H. Kolaczinski, Ambrose W. Onapa, Narcis B. Kabaterein,e Richard Ndyomugyeny,i Abbas S. L. Kakembo Simon Brooker. NEGLECTED TROPICAL DISEASES AND THEIR CONTROL IN UGANDA SITUATION ANALYSIS AND NEEDS ASSESSMENT, 2006
10. Lenk, E. J. et al. (2016) 'Productivity Loss Related to Neglected Tropical Diseases Eligible for Preventive Chemotherapy: A Systematic Literature Review', PLOS Neglected Tropical Diseases, 10(2), p. e0004397. doi: 10.1371/JOURNAL.PNTD.0004397.
11. Ortu, G. and Williams, O. (2017) 'Neglected tropical diseases: Exploring long term practical approaches to achieve sustainable disease elimination and beyond', Infectious Diseases of Poverty, 6(1), pp. 1–12. doi: 10.1186/s40249-017-0361-8.

12. Stolk, W. A. et al. (2016) 'Between-Country Inequalities in the Neglected Tropical Disease Burden in 1990 and 2010, with Projections for 2020', PLOS Neglected Tropical Diseases, 10(5), p. e0004560. doi: 10.1371/JOURNAL.PNTD.0004560.
13. ACT TO END NTDS EAST (2022) *Uganda | Act to End NTDs*. Available at: https://www.acteast.org/where-we-work/uganda.(Accessed 3rd April, 2023)
14. World Health Organization (2021). Ending the neglect to attain the Sustainable Development Goals: a road map for neglected tropical diseases 2021–2030. Available from: https://www.who.int/publications/i/item/9789240010352.
15. Vega J. Universal health coverage: the post-2015 development agenda. Lancet. 2013;381:179–80. doi: 10.1016/S0140-6736(13)60062-8.
16. Bangert, M., Molyneux, D.H., Lindsay, S.W. et al. The cross-cutting contribution of the end of neglected tropical diseases to the sustainable development goals. Infect Dis Poverty 6, 73 (2017). https://doi.org/10.1186/s40249-017-0288-0
17. Bizimana, P. et al. (2018) 'Capacity gaps in health facilities for case management of intestinal schistosomiasis and soil-transmitted helminthiasis in Burundi', Infectious Diseases of Poverty, 7(1), pp. 1–9. doi: 10.1186/s40249-018-0447-y.
18. Mazigo, H. D. *et al.* (2021) 'Primary health care facilities capacity gaps regarding diagnosis, treatment and knowledge of schistosomiasis among healthcare workers in North-western Tanzania: a call to strengthen the horizontal system', *BMC Health Services Research*, 21(1), pp. 1–9. doi: 10.1186/s12913-021-06531-z.
19. UNHCR 2021 Report
20. Kouadio, I.K., Kamigaki, T. & Oshitani, H. Measles outbreaks in displaced populations: a review of transmission, morbidity and mortality associated factors. *BMC Int Health Hum Rights* **10**, 5 (2010). https://doi.org/10.1186/1472-698X-10-5
21. Spiegel PB, Checchi F, Colombo S, Paik E. Health-care needs of people affected by conflict: future trends and changing frameworks. Lancet. 2010 Jan 23;375(9711):341-5. doi: 10.1016/S0140-6736(09)61873-0. PMID: 20109961.
22. Doocy, S., Lyles, E., Roberton, T. *et al.* Prevalence and care-seeking for chronic diseases among Syrian refugees in Jordan. *BMC Public Health* **15**, 1097 (2015). https://doi.org/10.1186/s12889-015-2429-3
23. Ministry of Health Uganda (2020) 'Sustainability Plan for Neglected Tropical Diseases Control Program'.
24. Fitzpatrick C, Nwankwo U, Lenk E, et al. An Investment Case for Ending Neglected Tropical Diseases. In: Holmes KK, Bertozzi S, Bloom BR, et al., editors. Major Infectious Diseases. 3rd edition. Washington (DC): The International Bank for Reconstruction and Development / The

World Bank; 2017 Nov 3. Chapter 17. Available from: https://www.ncbi.nlm.nih.gov/books/NBK525199/ doi: 10.1596/978-1-4648-0524-0_ch17

25. Liese B, Rosenberg M, Schratz A. Programmes, partnerships, and governance for elimination and control of neglected tropical diseases. Lancet. 2010 Jan 2;375(9708):67-76. doi: 10.1016/S0140-6736(09)61749-9. PMID: 20109865.
26. World Health Organization. (2012). Community-based interventions for the control of neglected tropical diseases. Accessed on 3rd November, 2024.
27. Marchal, B. et al. (2011) 'Neglected tropical disease (NTD) control in health systems: The interface between programmes and general health services', Acta Tropica, 120(SUPPL. 1). doi: 10.1016/j.actatropica.2011.02.017.
28. (Hagaman, A. K. and Wutich, A. (2016) 'How Many Interviews Are Enough to Identify Metathemes in Multisited and Cross-cultural Research? Another Perspective on Guest, Bunce, and Johnson's (2006) Landmark Study:', http://dx.doi.org/10.1177/1525822X16640447, 29(1), pp. 23–41. doi: 10.1177/1525822X16640447.
29. Hagaman, A. K. and Wutich, A. (2017) 'How Many Interviews Are Enough to Identify Metathemes in Multisited and Cross-cultural Research? Another Perspective on Guest, Bunce, and Johnson's (2006) Landmark Study', Field Methods, 29(1), pp. 23–41. doi: 10.1177/1525822X16640447.
30. 24Dworkin, S. L. (2012) 'Sample Size Policy for Qualitative Studies Using In-Depth Interviews', Archives of Sexual Behavior 2012 41:6, 41(6), pp. 1319–1320. doi: 10.1007/S10508-012-0016-6