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Towards Eliminating Discrimination of Persons Affected with Skin NTDs: The Need for Global Research to Map Associated Myths

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ABSTRACT

With more than one hundred and seventy countries and territories globally being endemic with a number of Neglected Diseases (NTDs), and more than ten among which exhibit skin conditions: Knowledge gaps breed myths, and discrimination thus thrives – limiting socio-economic options and upsetting the psychosocial buoyance of affected persons, and their families.

Knowledge shared through recent studies and dialogues of global stakeholders on the subject have highlighted that external drivers of stigma related to Skin NTDs are often the community, health staff, structures, laws and policies; thus, underscoring a strong need for engendering positive change through information, education, high level advocacy and actions of opinion leaders. Such studies and dialogues have established that to advance efforts to eliminate discrimination of persons affected with Skin NTDs, it is important to understand the complexity of the stigma, making it expedient to identify as many myths [associated with these conditions] as possible [globally] to create comprehensive knowledge-base as in instrument for heightened enlightenment & advocacy.

This paper posits that mapping all [or as many as possible] of these myths could serve as a strong tool amidst efforts of global and local NTDs stakeholders to eliminate discrimination of persons affected with Skin NTDs; and thus, proposes that some actions be undertaken by Skin NTDs stakeholders towards global research to map myths associated with Skin NTDs.

Global stakeholders can work to constitute and commission a research team that will create [simple] research indicators to harness feedback from Country NTD programs and implementing partner NGDOs about all myths encountered in their work with local communities. Such effort can create a data collection tool with capacity to collect data from multiple countries and selectively parse data into each country-specific dashboard [via solutions like Kobo Toolbox] and invite all country NTD programs to participate in the research by cascading the research data collection tool to all sub-district NTD programs, and local NTD-NGDOs.

Such research could benefit from preparation of comprehensive reports [inclusive of a section on data-use-ethics-guide by an expert panel], make publications and present same at key NTD [and global health] events towards advocating for its use in breaking down systems and community level barriers. This paper calls all stakeholders to action, in line with the 2030 roadmap.

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Introduction

Neglected Tropical Diseases (NTDs) are a group of infectious diseases prevalent in tropical and subtropical regions, affecting over 1 billion people, predominantly in low-resource settings, especially in low-income countries [1]. Neglected Tropical Diseases (NTDs) affecting the skin are regarded as "Skin NTDs" and include leprosy, lymphatic filariasis, yaws, and cutaneous leishmaniasis etc. Beyond physical morbidity, these conditions often are particularly stigmatizing due to their visible manifestations. These conditions often lead to severe social stigma, exclusion, and discrimination, economic hardship, and psychological distress, exacerbated by entrenched myths and misconceptions that associate them with curses, moral failings, or supernatural causes [2].

This paper explores the critical need for global research to systematically map myths associated with skin NTDs, emphasizing their role in perpetuating discrimination, making a case that undertaking a global research initiative to map these myths is essential for developing targeted interventions to eliminate discrimination against persons affected by skin NTDs. By identifying and addressing these myths governments and development actors can better engage through culturally sensitive interventions, and public health strategies can foster social inclusion and improve quality of life for affected individuals. The paper proposes a framework with an expanded explanation of the key components, implications, rationale, and proposed actions for a global research initiative to systematically map these myths as a strategy to combat stigma and promote social inclusion for persons with Skin NTDs.

The Burden of Skin NTDs and Associated Stigma

Skin NTDs present unique challenges due to their visibility, which amplifies social stigma. For instance, leprosy, despite being curable, is often linked to historical notions of "uncleanness," or associated with karma or moral failings, leading to ostracism, while in some places, yaws may be attributed to witchcraft, fostering fear and isolation [3,4]. Similarly, lymphatic filariasis, characterized by lymphedema or hydrocele, is, in some cases, misinterpreted as a divine punishment, or sometimes viewed as a hereditary condition or a sign of impurity, restricting marriage prospects or social participation, and resulting in social isolation [5,6]. These misconceptions are not merely anecdotal but are deeply embedded in cultural narratives, varying across regions and communities. The World Health Organization (WHO) estimates that skin NTDs affect over 150 million people, yet the social burden remains understudied [7,8].

These myths amplify stigma by creating fear, misunderstanding, and negative stereotypes. Stigma manifests in various forms, including exclusion from community activities, restricted access to healthcare, and discrimination in employment or marriage. Myths, such as the belief that skin NTDs are contagious through casual contact or inherited, perpetuate fear and misunderstanding, which in turn hinder treatment-seeking behavior, delay diagnosis, and prevent reintegration of affected individuals into their communities. Furthermore, women and marginalized groups are often disproportionately affected, compounding existing inequalities [9]. This paper thus posits that addressing these myths is fundamental to dismantling the social barriers faced by individuals with skin NTDs.

The Need for Global Research to Map Skin NTD Myths

Myths surrounding skin NTDs are diverse and context-specific, shaped by cultural, religious, and historical factors. For example, in some parts leprosy is linked to karma, while in some other parts, Yaws is attributed to witchcraft [10]. These beliefs influence community attitudes and healthcare delivery, yet there is no comprehensive global map of such myths. Systematic research is needed to identify prevalent myths by documenting myths across regions to understand their origins and variations. There is also a need to assess their impact by quantifying how myths contribute to stigma, discrimination, and health-seeking behavior, as well as the need to deploy learnings to inform interventions by developing evidence-based, culturally-tailored strategies that serve to counter misinformation.

A global research initiative would enable cross-country comparisons, highlighting commonalities and unique challenges. Such data could guide policymakers and health practitioners in designing effective anti-stigma campaigns. Thus, this paper will explore a systematic, comprehensive effort to identify, document, and analyze the myths and misconceptions associated with skin NTDs across diverse cultural and geographic contexts. The proposed mapping process would involve: Cataloging myths to identify specific beliefs about skin NTDs, such as their causes, transmission, or social implications, in different regions and communities; understanding their origins by exploring the cultural, religious, historical, or social factors that give rise to these myths; assessing their impact through evaluating how these myths contribute to stigma, discrimination, and barriers to healthcare access or social inclusion, and; documenting variations towards recognizing how myths are context-specific and vary across communities, necessitating a nuanced understanding of local belief systems.

By creating a global repository of these myths, stakeholders can gain insights into the root causes of stigma and tailor interventions to address them. For instance, a myth that leprosy is a divine curse in one community might be countered with religious leader-led education campaigns, while a belief in witchcraft as a cause of yaws in another region might require community-based storytelling to shift perceptions. Mapping myths provides a foundation for evidence-based, culturally sensitive interventions, making it a "strong tool" for reducing discrimination and fostering equity.

Proposed Research Framework

This paper proposes actions for a global research initiative to map myths associated with skin NTDs that stakeholders may undertake towards paving the way for a world where individuals with skin NTDs are free from stigma and discrimination. The initiative will benefit from inviting all country NTD programs to participate early-on in the process, fostering a sense of ownership and collaboration. This can be achieved through formal invitations by global stakeholders, such as WHO or the NTD NGO Network, where calls for participation are issued, outlining the goals and benefits of the research. Offering technical support, funding, or recognition to encourage country programs to join the initiative can also be great incentives for realizing participation. Also, engaging local stakeholders early in the research design process can serve to build trust and ensure that the research tools, instruments and processes are relevant and culturally appropriate. By involving country programs and local voices, the research becomes a global effort that aligns with national health priorities and strengthens local capacity to address stigma.

Creating Simple Research Indicators

A key consideration would be the development of consistent research protocols that ensure data comparability across countries, and enable global insights while respecting local nuances. This paper identifies the need to undertake the development of simple research indicators to collect feedback on myths from country NTD programs and NGDOs. These indicators must be measurable, standardized metrics designed to capture information about myths in a consistent and accessible way. Simplicity of the indicators is critical to ensure that they can be cross-examined and used across diverse contexts, including low-resource settings with limited technical capacity. Examples of such indicators might include: Prevalence of specific myths such as instances where community members believed any particular Skin NTD is caused by a particular myth; sources of myths where the research explores identifying whether myths originate from religious beliefs, cultural traditions, or misinformation; impact on behavior where the research interacts with proportion of individuals with skin NTDs who report to avoid healthcare due to stigma linked to myths, as well as; community attitudes where the research examines variations of discriminatory practices (i.e. exclusion from social events, employment etc.) attributed to specific myths. By keeping indicators straightforward, the research can ensure that data collection is feasible for local NTD programs and NGDOs, which often operate with limited resources and staff.

Harnessing Feedback from Country NTD Programs and NGDOs

Country NTD programs, typically managed by national health ministries, and local NGDOs are at the forefront of implementing interventions for skin NTDs. These entities interact directly with affected communities and encounter myths in their daily work. This paper proposes that the research collect feedback from these programs to identify myths in context by capturing the specific myths prevalent in local communities, which often tend to vary by region [11,12]. The research can also work with country NTD programs to document real-world impacts towards yielding understanding of how myths have been reported to influence community attitudes, healthcare access, and

social inclusion. One strong area of collaboration that the research will leverage is the rich existing networks of NTDs government and NGDO programs present locally which can enable utilizing the established infrastructure and activities of such NTD programs and NGDOs to gather data efficiently, dipping the need for any new systems. This approach ensures that the research is grounded in the lived experiences of communities and the practical insights of frontline workers.

A decentralized approach to data collection is proposed to involve cascading the research data collection tool to beyond national and district levels, onto sub-district NTD programs and local NGDOs, and this will involve:

- **Engaging Sub-District Programs:** Sub-district NTD programs, health facilities and workers are closest to affected communities and can collect granular data on myths from rural and underserved areas.
- **Partnering with NTD NGDOs:** Local NGDOs, often deeply embedded in communities, can provide qualitative insights and facilitate community participation in data collection.

In participating countries, the above will benefit from training and capacity building to ensure local personnel can use the research data collection tool effectively, including how to record and upload data. Community involvement can also be explored to encourage participation from affected individuals and community leaders in providing feedback towards ensuring that the data reflects diverse perspectives and lived experiences. This cascading approach maximizes the reach of the research, ensuring that data collection is inclusive and representative of diverse geographic and cultural contexts.

Developing a Data Collection Tool

This paper advocates for the creation of a robust data collection tool capable of gathering data from multiple countries. Tools like Kobo Toolbox, an open-source platform widely used in humanitarian and public health research, is highlighted as a potential solution due to its accessibility, flexibility, and ability to function in low-connectivity environments. Key features and considerations of the proposed tool include:

- **Multi-Country Data Collection:** The tool would be designed to collect standardized data across diverse regions, allowing for global comparisons while accommodating local variations.
- **User-Friendly Interface:** Simple forms or surveys that can be completed by health workers, community leaders, or NGDO staff with minimal training.
- **Offline Functionality:** Critical for use in remote areas with limited internet access, common in regions where skin NTDs are prevalent.
- **Data Parsing for Country-Specific Dashboards**: The tool would organize data into dashboards tailored to each country, enabling stakeholders to visualize and analyze myths specific to their context.

By using a platform like Kobo Toolbox, the research can streamline data collection, ensure data quality, and make findings accessible to stakeholders at both global and local levels.

Expected Outcomes of Mapping Skin NTD Myths

Such a global research initiative to map myths [as proposed in thus paper] could yield several outcomes chief of which would be achieving a comprehensive myth mapping. Populating a global database of myths associated with skin NTDs, can provide a foundation for a plethora of targeted anti-stigma interventions. Country-specific insights can also be a great outcome of such a research initiative through dashboards tailored to each country's context, enabling national programs to design locally relevant campaigns and community education efforts. The foregoing sets the stage for realizing evidence-based interventions where data on myths can guide strategies and inform targeted education and awareness campaigns, training for healthcare workers, or engagement with religious leaders to debunk misconceptions and reduced stigma by emphasizing targeted messaging that distill myths i.e. the cause and curability of any particular disease.

By debunking myths that deter treatment-seeking, stakeholders can reduce stigma, improve healthcare access, and increase early diagnosis and treatment adherence, resultantly reducing morbidity and leading up to improved health outcomes. Social inclusion for individuals with skin NTDs can also benefit a great boost due to how addressing myths can rapidly reduce discrimination, and enable affected individuals to participate fully in community life, employment, and education. Policy can also be impacted positively where research findings are used as valid tools to support advocacy for policies that prioritize stigma reduction, and align with global health equity goals. Global knowledge sharing can also profit from a centralized database of myths and interventions which can serve as a resource for stakeholders worldwide, fostering cross-country learning. This will strengthen global-local collaboration and foster partnerships between global stakeholders, country programs, and NTD NGDOs, enhancing coordination in the fight against NTDs.

Mapping myths is a critical step toward designing interventions that address stigma at its roots and potential strategies that could largely benefit from such a global research initiative include: education and awareness campaigns that use media and community engagement to debunk myths, emphasizing the medical nature of skin NTDs; community-based interventions that train local leaders and healthcare workers to advocate for inclusion, as well as; policy advocacy that stirs integration of anti-stigma measures into national NTD programs, as recommended by stakeholders .

Challenges and Considerations

Conducting global research on myths requires several considerations, including: cultural sensitivity to ensure research respects local beliefs without reinforcing stereotypes; resource constraints around securing funding and expertise for such a large-scale, cross-country study, and; data comparability when standardizing methodologies to allow for meaningful global comparisons. Where dynamic methodologies and interventions are introduced into the research structure, sustainability becomes a key consideration to cater for any long-term community engagement and policy integration to maintain impact. These challenging considerations can be addressed through partnerships of governments, international organizations as well as existing NTD networks to share resources and expertise, and by leveraging available technology for data collection and analysis.

Emphasis must be made on collaboration among global and local NTDs stakeholders, including international organizations, national health ministries, local healthcare providers, community leaders, and affected individuals. These stakeholders play complementary roles where global actors can coordinate large-scale research, secure funding, and develop standardized methodologies for myth mapping, and local stakeholders (i.e. country NTD programs) can provide contextual knowledge, ensure cultural sensitivity, and facilitate community engagement, as well as affected individuals offering lived experiences, ensuring that research learnings [and resultant actions] are grounded in their realities and priorities. This collaborative approach can help to ensure that efforts to map myths and address discrimination are inclusive, participatory, and aligned with global health goals, such as the WHO's 2021–2030 NTD Roadmap, which emphasizes reducing stigma and improving quality of life [13].

Role of Global Stakeholders

Global stakeholders, such as the World Health Organization (WHO) and NTD NGO Network, international NGOs, funding donors, and academic institutions, are well-positioned to initiate and coordinate such large-scale research effort due to their resources, networks, and expertise. This paper suggests that these stakeholders take a leadership role in constituting a research team by forming a multidisciplinary team of experts in public health, anthropology, sociology, and data science to design and oversee the research process. Commissioning the research can also be supported by securing funding and providing strategic direction to ensure the research aligns with global health priorities, such as the WHO's 2021–2030 NTD Roadmap, which emphasizes reducing stigma . This collaborative approach would enable leveraging the authority and reach of global stakeholders to mobilize resources and engage country-level NTD programs and local non-governmental organizations (NDGOs) focused on NTDs.

Conclusion

This paper builds upon the principles of the DevAxle 2025 Call to Action to Demystify Skin NTDs which deems mapping of myths associated with skin NTDs as a critical step toward eliminating discrimination and promoting social inclusion for affected individuals as discrimination against persons affected by skin NTDs is a significant barrier to their health and well-being, driven by myths that vary across cultural contexts. A [global] research to map these myths is urgently needed to inform evidence-based interventions that promote social inclusion and equity because, by systematically documenting these myths through such global research, stakeholders can develop targeted, culturally sensitive interventions that address the root causes of stigma.

The framework proposed puts forward a practical, scalable approach to mapping myths associated with skin NTDs by leveraging the expertise of global stakeholders, the infrastructure of country NTD programs, and the reach of local NGDOs. Through developing simple research indicators and deploying a data collection tool like kobo Toolbox, and cascading the research to sub-district levels, this initiative can create a global repository of myths while providing country-specific insights through tailored dashboards. This effort would empower stakeholders to design evidence-based, culturally sensitive interventions to combat stigma and eliminate discrimination, aligning with global health goals for equity and inclusion. By fostering collaboration and harnessing existing networks, the initiative offers a pathway to transform the social landscape for individuals affected by skin NTDs.

Future efforts should focus on securing funding, building partnerships, and translating research findings into actionable policies, and this paper offers a roadmap for improving the lives of individuals with skin NTDs. Ultimately, this proposed initiative aligns with global health priorities to ensure that no one is left behind due to preventable stigma and discrimination. Adopting an interdisciplinary approach and prioritizing community engagement is also vital, as such research can pave the way for a world where individuals with skin NTDs are free from stigma and discrimination. Translating research into action thus becomes a responsibility stakeholders must commit to, so that findings are used to inform and drive real-world actions such as anti-stigma campaigns, healthcare workers trainings, and advocacies for policy changes that integrate myth-busting strategies into national NTD [and broader health and social] programs.

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