JOURNALIST'S GUIDE TO

REPORTING ON NEGLECTED TROPICAL DISEASES

A comprehensive guide to support journalists covering neglected tropical diseases.









This comprehensive guide is designed for journalists and health communications professionals covering neglected tropical diseases (NTDs). By providing essential information, resources, and tips, this toolkit aims to equip journalists with the tools and knowledge to report on NTDs effectively and accurately.

UNDERSTANDING NEGLECTED TROPICAL DISEASES

NTDs have significant and far-reaching effects on a global scale – impacting more than one billion people in 149 countries and territories (World Health Organization [WHO]). As of 2024, the WHO currently classifies 21 conditions caused by a variety of pathogens (https://www.who.int/health-topics/neglected-tropical-diseases). NTDs are infectious diseases that primarily affect populations in tropical and subtropical regions and are characterized by their prevalence in low income communities with limited access to health services.

Individuals affected by NTDs often face chronic disabilities, disfigurement, stigma, and pain. As such, NTDs have substantial consequences for the health and well-being of affected communities, extending beyond the immediate health implications to impact education, economic productivity, and the overall socio-economic development of regions grappling with these diseases.



Teams go house to house to conduct a trachoma impact survey in Bac Kan province, Vietnam. Photo credit: RTI International/Nguyen Minh Duc

The distribution of NTDs is often linked to environmental conditions that favor the survival of disease vectors, such as mosquitoes and snails, responsible for transmitting various diseases and conditions. Additionally, regions with inadequate sanitation, water supply, and limited infrastructure are more susceptible to the spread of these diseases. Limited education and awareness in these areas further contribute to disease transmission and persistence. Women and children, people with disabilities, ethnic minorities, and geographically isolated populations often bear a heavier burden due to limited resources and the accessibility of health services.

Accurate and timely reporting on NTDs is an important component to ensuring that children with these diseases and conditions can flourish, people at risk of blindness from NTDs can see, and others at risk for disfigurement or disability can thrive in healthy communities.

EFFORTS TO CONTROL AND ELIMINATE NTDS

Efforts to control and eliminate NTDs involve a multifaceted approach that incorporates a variety of tools and approaches that can be used to prevent and manage NTDs. National governments, through their ministries of health or other departments, plan and implement services for people at-risk for or living with NTDs. To accurately report on this issue, reporters should familiarize themselves with these approaches and learn about the challenges to ending NTDs. The primary methods for NTD prevention are through mass drug administration, vector control, and improved water and sanitation. Case management is vital to early detection of NTDs and ensuring that those individuals receive quality clinical treatment.

- Mass drug administration (MDA) occurs where entire populations in endemic areas (where NTDs are prevalent) are treated with medications that target early stages of infection, helping reduce transmission of disease. This approach targets diseases like lymphatic filariasis, river blindness (onchocerciasis), and trachoma, among others, though not all NTDs have readily available treatment options.. MDA campaigns typically involve highly coordinated efforts and broad stakeholder involvement that may include national and local governments, pharmaceutical companies, NGOs, and foreign donor governments. MDA is often conducted in communities annually or biannually until the disease prevalence is reduced and, eventually, is no longer a public health problem.
- Vector control measures are crucial for NTDs transmitted by disease-carrying vectors such as black flies, mosquitoes, and house flies. Insecticide-treated bed nets, indoor residual spraying, and environmental modifications can reduce the risk of transmission.



A community member holding a dosage of LF medicine during a LF treatment campaign in Kilwa District, Tanzania. Photo credit: RTI International/Roshni Lodhia

- **Surveillance** involves surveys to assess the prevalence, or proportion of individuals in a population who have a disease or health condition, and distribution of disease. The data collected in surveys allows governments to understand disease burden, evaluate the effectiveness of NTD interventions, and inform public health policy and service delivery.
- Improved water, hygiene, and sanitation is another key component to NTD prevention. Enhancing sanitation infrastructure and promoting hygiene practices help prevent the transmission of certain NTDs. Access to clean water and proper sanitation facilities can reduce the prevalence of disease by decreasing transmission in the community.
- **Case management** is important for individuals living with the health impacts of NTDs. Case management involves thorough assessment, treatment planning, and coordination of care. It also includes providing patient education, monitoring treatment progress, and facilitating access to support services.

GLOBAL NTD POLICY AND INITIATIVES

The global response to NTDs is guided by comprehensive policies and strategic frameworks. The World Health Organization (WHO) Roadmap for NTDs 2030 serves as a pivotal document outlining ambitious targets and strategies for the control, elimination, and eradication of NTDs on a global scale.

The success of the WHO Roadmap and other global initiatives relies on the commitment and collaboration of diverse stakeholders, including governments, international organizations, research institutions, pharmaceutical companies, and affected communities. Stakeholders are called upon to contribute resources, expertise, and advocacy efforts to fulfill the ambitious goals set forth in these policy frameworks.

Country ownership and leadership is essential to successful NTD control and elimination efforts. From policy to MDA logistics, data management, and supply chain logistics, the delivery of NTD services requires financial and human resources, coordination, and multi-sector involvement. Donor governments and bilateral aid support countries in these

NTD elimination

NTD elimination is within reach. Over the last two decades, coordinated efforts have resulted in considerable progress towards reducing the burden of NTDs. As of November 2024, 54 countries globally have eliminated at least one NTD, surpassing the halfway point to the target set forth in the World Health Organization Road Map for NTDs. These results stem from coordinated efforts involving governments, international organizations, NGOs, and affected communities.

Other key achievements include:

More than 2.1 billion NTD treatments were donated to countries in 2023.* Since 2011, 27.7 billion treatments have been delivered.

1.62 billion people required NTD interventions in 2022, a 26% decrease from 2010.

As of December 2023, 19 countries had eliminated LF as a public health problem, while an additional 10 countries were in the process of validating elimination.

As of 2023, 18 countries had eliminated trachoma as a public health problem.

* = Data according to WHO Global Report on NTDs 2024

efforts. Donors like the U.S. Agency for International Development (USAID), the Bill & Melinda Gates Foundation, and others support a range of activities, including MDA, programmatic monitoring, healthcare infrastructure development, and community-based interventions.

MEDIA AND NTDS

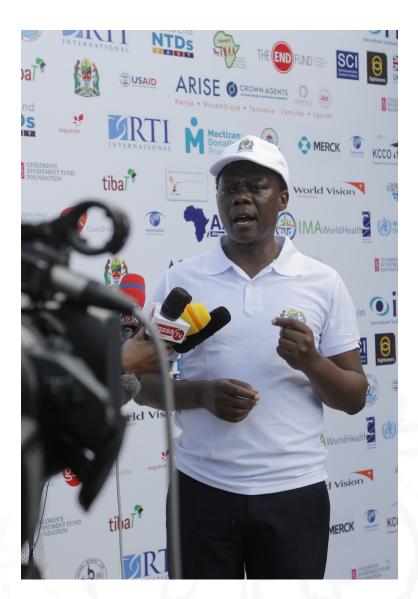
Media plays a pivotal role in shaping public perception, fostering awareness, and influencing policy decisions. In the context of NTDs, journalists and media professionals, through timely and accurate reporting, can drive positive change. This section explores the multifaceted impact of media in NTD reporting and addresses common challenges faced in this domain.

News opportunities

As countries work towards eliminating NTDs, there are a number of newsworthy opportunities for reporters to cover. Mass drug administration and disease surveys occur at varying rates by country, but require substantial stakeholder involvement from the national, district, and community levels. Ministry officials, district governments, and local community members and leaders are examples of people to interview.

Social mobilization

Social mobilization is a key component to the success of NTD interventions. Prior to MDA or disease surveys, social mobilization methods are used to increase awareness in communities and encourage individuals to participate. Communications and media campaigns can play an important role in increasing



Deputy Minister of Health, Dr. Godwin Mollel addresses the media at the World NTD Day celebration and launch event for Tanzania's Master Plan and Sustainability Plan for NTDs gather in Nyerere Square Grounds in Dodoma, Tanzania. Photo credit: RTI International

the number of participants who are aware of an intervention or survey (including timing, location, methods of delivery), address misconceptions about NTDs and NTD medicines, and encourage behaviors such as hand and face washing that help prevent the spread of disease.

Behavior change

The media can also use accurate, timely communications which in turn influence behavior change. Accurate reporting can motivate individuals and communities to make positive changes in their behaviors and practices related to NTDs by informing people of practices that prevent the spread of NTDs. Some keys to successful behavior change reporting include:

- **Consistent reporting:** Behaviors take time to change at scale. Regular reporting and updates can be a force for change.
- **Share preventive measures:** The spread of some NTDs can be limited through preventive measures like proper hygiene, sanitation, and treatments through MDA.
- **Feature leaders and experts:** Interviews and features profiling respected leaders and/or experts can be influential. Journalists should take the time to find out which community members influence decision making.
- **Utilize partnerships:** Collaborate with the Ministry of Health (MOH) and international organizations to strengthen dissemination and learn what support from media is needed.

Advocacy

Media plays a crucial role in delivering accurate information. That information may lead to changing policies, influencing public opinion, and promoting accountability. Journalists can foster transparency and public understanding by highlighting government policies, global initiatives, and funding commitments. Reporting on NTD successes demonstrates that progress is achievable, which in turn can lead to support. Investigative reporting and analyses can expose gaps in NTD control strategy and/or financing while advocating for evidence-based interventions.



Ugandan State Minister for Karamoja Dr. Maria Goretti Kitutu, West Pokot County Executive Committee member for health and sanitation Ms Christine Apokoreng, Dr. Wycliffe Omondi, NTD Program Manager, Kenya Ministry of Health, Member of Parliament for Amud. Photo credit: RTI International

NTD stigma, misinformation, and misconceptions

In many NTD-endemic communities, pervasive stigma, misinformation, and misconceptions pose major challenges to NTD elimination efforts. Accurate reporting and storytelling can help correct misinformation and reduce stigma.

- Lack of knowledge: In many communities, there is a lack of understanding about NTDs and the health services available, sometimes attributing NTDs to supernatural forces or lacking clarity on transmission modes.
- **Misinformation**: Rumors and misinformation about NTDs, medicines available, and eligibility of individuals to receive treatment, for example pregnant/breastfeeding women, can impact the reach of treatment to communities. The media plays a role in providing accurate information about NTD causes, transmission, and treatment.
- **Social stigma:** Fear, discomfort, and misunderstanding can lead to social isolation due to visible deformities or disabilities which can contribute to depression, anxiety, and low self-esteem among affected individuals. This can also impact individuals in seeking health services.
- Cultural beliefs: Myths and curses associated with NTDs can reinforce stigmatization.
- **Humanizing individuals:** Sharing stories that highlight the resilience of people affected by NTDs can help foster empathy and compassion for affected communities.

Challenges and barriers to reporting on NTDs

Reporting on NTDs presents several challenges and barriers, which can impact the quality and depth of media coverage. Addressing these challenges requires a concerted effort from journalists, media organizations, health communicators, and stakeholders involved in NTD control. Some of the key challenges include:

- **Limited awareness:** The neglected nature of NTDs can result in a reduced sense of urgency. Due to lack of public awareness, journalists may need to provide more background information to increase understanding and generate interest in NTD stories.
- **Stigma:** Some journalists may be hesitant due to fear of perpetuating stereotypes or causing harm to individuals. However, the media can play an important role in accurately reporting which can reduce discrimination and promote social inclusion.
- **Complexity:** NTDs are complex and involve scientific and technical jargon that may be hard to pronounce, understand, and difficult to explain to the public. Moreover, every country has distinct political, economic, and cultural factors that can be a barrier to delivering balanced reporting.
- **Limited data and research**: For many decades, NTDs were poorly understood and often understudied, making it difficult at times to find reliable sources and statistics on the prevalence, prevention, treatment, and impact of NTDs. See NTD Reporting Resources at the end of this document for regularly updated resources
- Competing health priorities: Many countries face a range of health challenges, and NTDs may not always be a top priority for media coverage when compared to more high-profile health issues like HIV/AIDS or malaria.
- **Logistical challenges:** Many NTDs are prevalent in geographically isolated, difficult to access, or insecure regions, which can make reporting more difficult to achieve.

STORYTELLING TECHNIQUES FOR NTD REPORTING

In NTD reporting, the art of storytelling plays a crucial role in connecting with audiences, raising awareness, and fostering empathy. By amplifying personal narratives, respecting diverse perspectives, and approaching interviews with sensitivity, media professionals contribute to the broader goal of humanizing the NTD narrative. Key opportunities to conduct NTD reporting are during mass drug administrations and disease surveys.

Effective journalism for NTDs often utilizes one or more of the following techniques:

- **Contextualizing NTDs:** Provide background on the specific NTD, its prevalence, and the affected regions. Help the audience understand the broader socio-economic and cultural factors influencing the spread and impact of the disease.
- **Humanizing the Narrative:** Feature personal narratives that highlight the human side of NTDs. Share stories of resilience, courage, and community efforts to overcome challenges associated with these diseases.
- Visual Storytelling: Incorporate visual elements, such as photographs or videos, to capture the
 faces and environments of those affected and/or those working to deliver health services, this
 provides a visual connection that enhances the storytelling impact.
- **Explaining the Science:** Break down complex scientific concepts into accessible language. Use analogies and metaphors to make the information relatable to a broader audience without compromising accuracy.

Human-centered storytelling

Oftentimes, human-centered stories have the most impact with audiences. These stories show the impact of NTDs while humanizing the issue, create emotional connection that can motivate individuals and communities to take action, and help the public understand complex health issues by showing real life examples. It is always important to clearly communicate the purpose of the story and obtain informed consent for sharing personal experiences, particularly when reporting on a person's health status.

Some key characteristics of impactful human-centered stories include:

- **Empathy:** Human-centered storytelling emphasizes understanding and sharing the feelings of the individuals involved.
- **Authenticity**: Journalists should focus on presenting real people with genuine emotions, challenges, and triumphs.
- **Relatability:** While NTDs aren't experienced by everyone, reporting should be relatable to a broad audience by focusing on universal themes and emotions.
- **Visual Elements:** Human-centered storytelling often incorporates visual elements, such as photographs, videos, or illustrations, to enhance the emotional impact of the narrative.
- Context and Background: While focusing on individuals, human-centered storytelling also
 provides accurate background information and context, particularly with regards to oftmisunderstood NTDs.



Many communities mobilize in support of NTDs, providing opportunities to engage and report on NTD's impact on communities. Here, students march in support of NTD interventions in Nepal. Photo credit: Brijesh Kumar/RTI International

Ethics and Inclusivity in NTD Reporting

Maintaining ethical standards and promoting inclusivity in NTD reporting is essential for responsible journalism. This section delves into responsible reporting, key ethical considerations, the use of inclusive language, accuracy in reporting, and guidelines for using photography and video in NTD stories.

Key Principles:

Respect and Empathy:

- Be mindful of cultural sensitivities and local customs.
- Consider the potential for trauma associated with NTDs.
- Uphold the dignity of individuals affected by NTDs.
- Focus on human stories while avoiding sensationalism.

• Accurate and Inclusive Reporting:

- Use clear, respectful language that avoids perpetuating stereotypes or stigmatization.
- Rely on authoritative sources like World Health Organization (WHO), MOHs, and reputable research institutions to ensure factual reporting.

• Transparency and Public Trust:

- Be transparent about the purpose and impact of your reporting.
- Obtain informed consent from individuals before sharing their stories.

Educational Role:

- Use your reporting to debunk myths and misconceptions about NTDs.
- Provide accurate information to contribute to public health literacy.

By adhering to these principles, journalists can contribute to responsible media coverage of NTDs, fostering public understanding and supporting efforts to eliminate these devastating diseases.

Doing This:

- Human-centered approach
- Focus on resilience and agency
- Apply empathy
- Use inclusive language
- Balanced representation of challenges and solutions
- Educational context
- Respect for privacy
- Avoid sensationalism
- Community engagement
- Accuracy
- Diverse perspectives



Can Lead to This:

- Preserve dignity
- Reduce stigma
- People use health-seeking behaviors
- More inclusive, understanding, and supportive society
- Improved public understanding of NTDs
- Build momentum for NTD policy
- Communities engaged in NTD control and elimination

Using Photography and Video for NTD Reporting

Photos and videos are a crucial component of effective human-centered storytelling for NTDs. These visual elements help bring a story to life and further increase the connection between the featured individuals and communities with your audience. Use the following techniques to maximize the impact of your stories while preserving the dignity, privacy, and respect that is deserved by individuals and communities impacted by NTDs.

- Clear Consent Process: When capturing images or videos, obtain informed consent from individuals involved. Clearly explain the purpose, potential reach, and use of the visuals, and respect their right to refuse participation.
- Respecting Privacy: Avoid invasive or exploitative imagery that compromises the privacy of individuals. Use visuals that convey the story while respecting the dignity of those depicted.
- Challenging Stereotypes: Choose visuals that challenge stereotypes associated with NTDs.
 Portray individuals in diverse contexts and showcase their strength and resilience rather than perpetuating victimization.
- Humanizing Portrayals: Present individuals with dignity and respect in visual storytelling. Capture the humanity and resilience of those affected by NTDs without resorting to sensationalism.



Children in Nepal play with a photographer's camera during an NTD activitity in the community. Photo credit: RTI International

YOU CAN BE THE DIFFERENCE

Global efforts to control and eliminate NTDs continue to show incredible progress. By understanding the prevalence, distribution, and challenges associated with NTDs, journalists play a pivotal role in amplifying the voices of affected communities and shedding light on the complexities of these diseases, which can result in increased awareness and resources dedicated to NTDs.

Through storytelling that embraces the principles of empathy, inclusivity, and ethical representation, journalists have the power to reshape narratives surrounding NTDs. By addressing stigmas, debunking misconceptions, and humanizing the stories of those impacted, timely and accurate reporting can lead to increased understanding and galvanizing support for NTD elimination efforts.

As journalists, you have the unique ability to bridge the gap between complex health issues and public understanding. The stories you tell can contribute to the realization of a future free from the burdens of NTDs.

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If you have questions or need more information, please contact <u>ActEast@rti.org</u>

ABOUT ACT TO END NTDS | EAST

The USAID Act to End Neglected Tropical Diseases | East program supports 13 countries across Africa, the Americas, and Asia to achieve NTD control and elimination goals. Building on over a decade of USAID investment, Act | East employs cost-effective public health strategies to eliminate lymphatic filariasis, trachoma, and onchocerciasis where feasible; strengthen health systems to deliver NTD services; and establish sustainable, countryled platforms for disease control and surveillance. These efforts support governments to integrate NTD services into resilient health systems.

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NTD REPORTING RESOURCES

Resources for expanding NTD knowledge, data sources, and advocacy:

- World Health Organization (WHO) Neglected Tropical Diseases: The WHO provides comprehensive information on NTDs, including global strategies, reports, and fact sheets.
 - WHO Global report on neglected tropical diseases 2023
 - Ending the neglect to attain the Sustainable Development Goals: A road map for neglected tropical diseases 2021–2030
 - A sustainability framework for action against neglected tropical diseases 2021–2030. Ending the neglect to attain the sustainable development goals
- USAID NTD Fact Sheet: Working to Protect Against Neglected Tropical Diseases
- World NTD Day: Campaign materials, reports, and infographics that highlight the impact of NTDs and ongoing efforts to address them.
- Institute for Health Metrics and Evaluation (IHME): Hub for data, research, analysis, and tools for all diseases, including NTDs
- NTD Toolbox: Practical guidance, tools, and resources for NTD program managers
- More than Medicine: Eliminating Trachoma in Mozambique: A short video demonstrating trachoma surveillance
- More than Medicine: Nepal's Journey to Eliminate a Disease: A short video focusing on LF MDA.