

Stronger together: evidence for collaborative action on neglected tropical diseases

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This editorial has been written by programme leads at the Liverpool School of Tropical Medicine in the UK to condense the learning shared across articles. Articles within this supplement have been written and led by authors in Nigeria and Liberia, and informed by learnings from across the partnership including from our partners in Ghana and Cameroon and articles previously published. Early career researchers were supported throughout the COUNTDOWN programme to publish evidence and lead the production of impactful papers. Decision makers and local implementers from each context are also authors on the papers within the supplement and were supported to engage with the writing process.

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Background

Neglected tropical diseases (NTDs) are a group of 20 diseases of poverty that frequently place devastating human, social and economic burdens on some of the most marginalised populations globally.^{1,2} Over the last three decades, coordinated advocacy has resulted in NTDs receiving increased attention financially, politically and academically. The London Declaration on NTDs launched in 2012 and succeeded by the Kigali Declaration in 2022 intensified programme momentum and saw donor countries, philanthropists, private sector companies, non-governmental organisations, academia and research organisations collaborate to find solutions for the prevention, control, elimination or eradication of many of these diseases. For example, ‘42 countries, territories and areas have eliminated at least one disease’.² Yet, we still have far to go on our journey towards achieving many of the goals and targets for the control of NTDs. To do this, we must now look backwards to move forwards, thinking critically on what has supported programmatic gains and what we could do better.

Since the first NTD roadmap (2012–2020) ‘Accelerating work to overcome the global impact of NTDs’, there have been many positive shifts in the ways in which we collaborate as an NTD community and in whose knowledge and expertise we prioritise.³ For example, we have learned to reduce our reliance on medicalised perspectives in favour of strengthening people-centred services that are directed by the needs and priorities of affected persons; to think innovatively about mechanisms for co-implementation of services across diseases through shared community delivery platforms; to prioritise integration of programmes with health systems through shared operating structures; to consider how to effectively measure interventions through the creation of clear epidemiological targets; and to prioritise coordination between

funders and implementing partners under the direction of national priorities.² These learnings are reflected within the three pillars that support the strategic direction of the NTD community for the next decade, as outlined within the current NTD roadmap: ‘Ending NTDs: together towards 2030’. Transcending these pillars is the recognition that by working together we can capitalise on the learnings of the past, to move forward for the next decade.²

Togetherness was a central value of the COUNTDOWN: Calling Time on Neglected Tropical Diseases implementation research consortium (hereafter COUNTDOWN). COUNTDOWN was a UKAID-funded 7-y (2014–2021) research programme, led by the Liverpool School of Tropical Medicine with partners in the four operating endemic countries, Ghana, Liberia, Nigeria and Cameroon. We focused on delivering high quality evidence on cost-effective, scalable and sustainable solutions necessary to control and eliminate seven NTDs (trachoma, schistosomiasis, onchocerciasis, lymphatic filariasis and three soil-transmitted helminths) that collectively have been responsible for 90% of the total global burden of NTDs. The research took a broad health system approach by conducting research at each of the healthcare layers from policy to community and individual. This supplement synthesises evidence from different studies conducted across these levels from within the COUNTDOWN programme.

COUNTDOWN: calling time on NTD

COUNTDOWN brought together researchers from a range of backgrounds and disciplines, healthcare providers, policymakers, laboratory scientists, research uptake specialists, Ministries of Health and Non-Government Development Organisations to bridge the knowledge to implementation gap for shared health

impact. Across contexts, COUNTDOWN worked proactively and collaboratively with health policymakers and NTD programme implementers at country level to disseminate research findings on an ongoing basis and to help ensure that the evidence generated was translated into action and mainstreamed within NTD programmes and health systems. It also consolidated the narrative of research to policy change in an accessible manner, supporting evidence-informed policy at community, local (district/state), national and international levels.

COUNTDOWN's multidisciplinary implementation research approach and, in particular, the use of social research to co-produce innovative solutions and adaptations to NTD programmes across the four African countries, generated new evidence and policy/practice uptake that contributed to the reduction in morbidity, mortality and poverty associated with NTDs. The research presented in this supplement demonstrates how barriers to access can be overcome while strengthening health systems and mass drug administration (MDA) approaches, to support more equitable service delivery and empower those living with NTDs. COUNTDOWN conducted 20 research projects while ensuring the development of sustainable research capacity among communities, health systems actors and organisations.

Across the COUNTDOWN consortium we have learnt many lessons that will support strategic and ongoing action to help end NTDs and achieve the WHO road map's goals.

They are reflected within this special supplement with key learnings synthesised and aligned to the NTD roadmap strategic pillars below.

Accelerate programmatic action

To accelerate programme action that is equitable, the articles included in this supplement highlight the need for innovation at the local level. Within COUNTDOWN, we utilised an implementation research approach that embedded NTD stakeholders within research teams to successfully support health systems strengthening to ensure that no one is left behind within NTD programme delivery. In their papers, Piotrowski et al. and Lar et al. emphasise how this approach led to the prioritisation of alternative methods of medicine distribution, community sensitisation and mobilisation, particularly within contexts where NTDs are emergent, for example, urban areas, to enhance programme access.^{4,5} New approaches to ensure drugs are available within health centres are also recommended to support the 'mop up' of missed populations, a recommendation that has been adopted by the NTD programmes across Nigeria and Liberia.⁴ Piotrowski et al. also further articulate an inclusive, localised approach to planning and implementing MDA that was developed, piloted and scaled-up across two Nigerian states to improve programme equity.⁴ Across these studies, innovations were identified by strengthening the research capacity of programme implementers and partners to use creative research approaches such as social mapping with diverse population groups for meaningful community and gatekeeper engagement and solution finding.⁵

Looking beyond MDA, the articles within this supplement also document how we have created space within national NTD programmes to develop effective NTD management interventions

within the primary healthcare (PHC) system. For example, we have worked to combat female genital schistosomiasis (FGS), a neglected stigmatising condition that severely affects the lives of 56 million girls and women in sub-Saharan Africa. Initial research to understand the stigma and treatment barriers surrounding FGS in Ghana (published elsewhere)⁶ was utilised to inform learning and innovation in Nigeria and Liberia, where FGS services have now been embedded into PHC for the first time.⁷⁻⁹ Implementation research in Nigeria and Liberia has been successful in supporting national Ministries of Health to create and operationalise FGS intervention strategies in both countries. These were the first projects globally to provide FGS diagnostic and treatment services at primary care level.

The process of FGS intervention development is highlighted by Oluwole et al., with each country context beginning by highlighting and addressing the knowledge gap related to FGS among system stakeholders and communities.⁸ Subsequently, utilising a quality improvement methodology that engaged community and health system stakeholders, the co-production of key steps to improve diagnosis and treatment for FGS are described by Nganda et al. and Piotrowski et al.^{7,9} Intervention steps included raising awareness and capacity, examining and increasing healthcare infrastructure and workforce skills, developing syndromic management tools and co-producing context-relevant operational tools and technical guidance for implementation.^{7,9} The articles in this supplement emphasise how by prioritising co-production within quality improvement processes, there was reduced stigmatisation of girls and women affected by FGS and an increase in available and accessible treatment. The approach increased political commitment, country ownership and sustainability by developing extensive evidence for policy in partnership with national NTD programmes and other health systems stakeholders. Nganda et al., Oluwole et al. and Piotrowski et al. present a harmonised call to action for funders and policymakers to build upon these pilot studies by continuing to generate awareness of FGS across the health system and communities; ensuring that praziquantel is available in PHC settings; and continuing to strengthen the capacity of health workers in endemic areas.⁷⁻⁹ The lessons presented here must be considered so that the lives of women and girls, who have for too long been neglected, can be improved.

Intensifying cross-cutting approaches

COUNTDOWN explored the advantages and disadvantages of integrating services across NTDs and mainstreaming programmes within health systems to consider how these approaches can enhance stakeholder collaboration and support to strengthen health systems. We considered the mainstreaming of NTD services in relation to multiple systems building blocks, with a dominant focus on service delivery and the health workforce.

Health workers and community drug distributors (CDDs) are the lynchpins of MDA for NTD control and elimination. However, in many settings, health worker shortages and challenges in staff motivation can negatively impact health workforce performance. By working closely with CDDs, we were able to make recommendations for enhanced packages of support, and their integration into the wider health system, to enable more

informed and responsive policy and programming. For example, within this supplement, Kevin et al. consider factors associated with job satisfaction among CDDs supporting the Nigerian NTD programme with the goal of identifying opportunities to improve job satisfaction in support of NTD control and elimination efforts.¹⁰ Their findings reveal that adaptation of training structures to include multiple health staff cadres (beyond PHC workers) in CDD training would strengthen satisfaction. Additionally, they emphasise the need to ensure CDDs are not out of pocket during NTD activities through the provision of remuneration for transport fares.

The critical importance of CDDs and other PHC workers became paramount during the coronavirus disease 2019 (COVID-19) pandemic. In their study, Yahemba et al. expand the understandings presented by Kevin et al. to stress how health worker support packages need to look beyond practical elements to also consider emotional well-being.^{10,11} Strengthening the capacity of health workers to critically analyse their own experiences, including the stressors they faced during COVID-19, has informed the co-development of recommendations in order to best support and prepare the health workforce for future pandemics and during routine service delivery. Similarities in these studies across contexts, and during health systems shocks, exemplify the critical importance for us as an NTD community in continuing to advocate for and support the needs of the health workforce, who are often overstretched and overworked but are the cornerstone of ongoing service delivery.

By focusing on gender, equity and rights, COUNTDOWN helped ensure that NTD programming was informed by the experiences of people affected by NTDs. The use of participatory research methodologies to document the everyday realities of people affected by NTDs described within the paper by Adekeye et al., emphasises the importance of addressing stigma and improving access to health services to enhance the overall well-being of people affected by NTDs.¹¹ Social cohesion and being recognised as part of an empowered community were key impacts of photovoice activities described by Adekeye et al.¹² This social cohesion among study participants and co-researchers supported the subsequent design of a peer support group intervention in Kwara and Kaduna states in Nigeria, as described by Chowdhury et al.¹³ The peer support group intervention took a holistic approach to disease management, disability and inclusion activities, delivered in an order that was prioritised by group members, and spanning from livelihood support to wound management. Early recognition of NTD signs and symptoms was also identified as critically important to reduce disease progression and the risk of morbidity. Thus, simultaneously to the development of the peer support group intervention, Lar et al. describe the introduction of an integrated training curriculum for community health workers and primary health providers for the case detection and diagnosis of prominent skin NTDs, including lymphoedema, hydrocele, leprosy and Buruli ulcer in the Ogun and Kaduna states.¹⁴ Through these studies, COUNTDOWN was able to move beyond a predominantly biomedical approach to NTD management to address support needs across the health-seeking continuum from a holistic perspective and, including mental health and well-being, generated new solutions for the integrated management of NTDs.

Change operating models and culture to facilitate country ownership

Throughout this supplement, we highlight the value of integrating government stakeholders at regional, national, subnational and local levels and people affected by NTDs in participatory action-oriented research. Recognising the need for different forms of knowledge (including intersectoral) production, across levels of the health system and with a variety of community stakeholders was essential for all community-based programmes. Participatory action-orientated approaches often required a paradigm shift to bottom-up planning and implementation, with consideration of the contextual realities and resources available, as described by Piotrowski et al.⁴ Our studies demonstrate the proactive approach taken by government actors, in partnership with researchers, to better understand the NTD programme needs of communities and to design and carry out an innovative NTD research agenda, which was led by national ministries. Embedding the research within the national programmes meant that many of the research teams had dual roles as researchers and implementers/policymakers, which helped to ensure that the research was relevant, country-driven and locally owned.

In two states of Nigeria, a participatory action research approach that embedded the use of learning health system principles, resulted in a new intervention that enhanced community engagement and stakeholder participation to identify and implement locally driven MDA strategies. Piotrowski et al. describe how the intervention employed multilevel health system working groups, capacity-strengthening workshops and participatory tools to identify nine key steps to support best practice for inclusive planning and implementation in disease programmes.⁴ This evidence can support health systems to embed continuous cycles of learning and reflection so they can sustainably and equitably reach those affected by NTDs who have been repeatedly missed. Developing and applying operational tools created by COUNTDOWN (e.g. the Standard Operating Procedure and Participatory Guide for Planning) has supported national programmes to be able to identify and engage more stakeholders (including community leaders, religious leaders and local government) to increase the acceptance of MDA; establish new integrated case detection services; and to guide programmes in navigating complex donor funding climates that impact on the planning and delivery of services and are critical factors in evaluating the scale-up and sustainability of interventions.

Legacy

When COUNTDOWN began, our vision was to work collaboratively to produce evidence that could increase the effectiveness of NTD programmes, with a focus on reaching poor and vulnerable groups and highlighting inequities, resulting in more people accessing appropriate interventions and receiving necessary treatments. The value of strengthening the research uptake process through early involvement of stakeholders was crucial because it increased the acceptability and sustainability of interventions. COUNTDOWN increased trust among those affected by NTDs (predominantly the poorest and most disadvantaged) through participation in, and ownership of, the research; by

using a range of dissemination tools and materials that were accessible and understandable to identified target audiences; and by targeted dissemination of resources through relevant groups (religious bodies, professional associations, youth groups, etc). COUNTDOWN involved policymakers, practitioners and other actors throughout the research lifecycle to facilitate and contribute to the use of research evidence. This helped sensitise stakeholders to the research and ensure the acceptability of interventions; ensure gender equity was central to thinking; engage strategic partners outside of the NTD programmes (e.g. disability organisations to help address stigma); and ensure the research was appropriate and relevant to country need and responsive to any arising gaps that were identified.

In addition to this supplement, COUNTDOWN produced 57 peer-reviewed research articles; two podcasts on how to effectively/ethically engage communities in research and how participatory research methods can be used to make NTD services more acceptable to vulnerable groups; a webinar attended by over 150 people from 20 countries that focused on disseminating the latest COUNTDOWN research, with a discussion on how findings and progress made can be understood and applied in the context of the WHO NTD Roadmap 2030 ; and a cross discipline toolkit for participatory research methods used by COUNTDOWN. Nineteen policy briefs (<https://countdown.lstmed.ac.uk/publications-resources/policy-briefs-and-documents>) have been produced over COUNTDOWN's lifetime. Extensive efforts were made throughout the programme to ensure that research findings were accessible and relevant to non-technical audiences, for example, by using photovoice stories, cartoons, radio broadcasts, podcasts and TV interviews.

COUNTDOWN's legacy will be championed by the many people with whom we have collaborated, particularly people affected by NTDs and close to community health providers, who are the driving force within NTD programmes. We would like to thank all the authors for the time they spent preparing the manuscripts and for sharing their valuable experiences and findings in an open and transparent way. Many thanks to our reviewers for their time and constructive comments and advice.

We hope that the research knowledge generated through COUNTDOWN will continue to contribute to reducing the morbidity, mortality and poverty associated with NTDs through increasing knowledge and capacity in line with the WHO NTD roadmap. By taking a health system approach to co-production we hope that we have shown how by working together across research disciplines; together with affected persons and their communities; together with national governments and their health systems; together across diseases and geographic boundaries; and together as scientists and programme implementers, we can achieve more on our journey to 2030.

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