



Taking forward a holistic research agenda for mental health of people affected by neglected tropical diseases

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In this editorial for the *International Health* supplement on mental health, stigma and neglected tropical diseases (NTDs), the essential consideration of mental health and well-being in the field of NTDs is highlighted, based on the high level of comorbidity and given the identification of emotional and social consequences as a priority of people living with NTDs. The re-establishment of a principle of person-centred care in global normative frameworks means that research is needed to establish what works in disease management, disability and inclusion, alongside major global investment in the elimination of NTDs. Research in this area is growing rapidly, although it is still at a stage of understanding prevalence and risk factors, piloting interventions and early stages of service development. There remains far to go to provide the evidence required to support national NTD programs to fully integrate mental health and stigma components to their services.

Any family member, clinician or person affected by an NTD will have a deep sense of the emotional consequences of living with these conditions. The distress experienced by the people affected is demonstrated in the high rates of comorbidity with mental health conditions, increased rates of suicide and a negative impact on overall recovery and rehabilitation. On top of any chronic painful or disabling symptoms, the experience of being stigmatised and socially excluded because of the condition you are living with is one that is often described by people as worse than the physical illness itself.

Responding to this social suffering was the driving motivation for the NTD movement throughout its long history as a disparate group of organisations addressing different diseases. Somehow, the huge advocacy success of its emergence as a distinct unified field with a strong, target-driven elimination agenda was accompanied by a relative neglect of those already affected. However, 10 y after the original London Declaration, the Kigali Declaration strongly asserted the importance of putting people and communities at the centre of NTD response.^{1,2} Elimination and management approaches are complementary, but it is only recently that the importance of both has been endorsed at the highest levels. A much more holistic approach to supporting people affected by

NTDs now underpins major global normative guidance like the World Health Organization (WHO) NTD Roadmap 2021–2030,³ although this has yet to be followed by commensurate investment. The roadmap and aligned WHO guidance on mental health and NTDs⁴ call for a more person-centred framework for NTD programming. Various actors in the field, from national programs to civil societies and researchers, have embraced this paradigm shift and are working to promote holistic responses to all facets of the NTD experience and we have seen a proliferation of research and guidance to support implementation programs.⁵

In this supplement, we received a diverse range of research in the area of mental health, stigma and NTDs, demonstrating the way that this field is growing and maturing. Five years ago, priorities for disease management, disability and inclusion in NTD research were identified.⁶ The articles in this supplement address many of these issues. First, there are valuable contributions to understanding the problems in more detail and questions of prevalence, associated risk factors, causal mechanisms and prognosis in the comorbidities between NTDs and mental ill health. Second, reflecting that much of this research comes from actors strongly rooted in implementation practice, there are evaluations of field interventions and their impact on mental health and social outcomes from Congo, Nigeria and India. Stigma has long been recognised as a major contributor to mental distress, but effective interventions exist, and we now routinely see comprehensive approaches where this is an integral component—with livelihoods, peer and caregiver support, and others—addressing social determinants alongside treatment provision.

There is notable and welcome collaboration evident between researchers, implementing agencies and policymakers in the authorship in many of the papers. Importantly, several of the articles use approaches that champion co-production with people living with NTDs. Throughout the supplement we have sought to include the voice of people affected by NTDs, many of whom are also represented on our Editorial Committee. We include here articles that demonstrate the profound personal and social impact of living with an NTD, e.g. the often unrecognised but

highly stigmatised condition of female genital schistosomiasis. At the same time however, we share the exciting emergence of representative organisations of affected people, speaking increasingly confidently to impact policy and investment in the support they need and playing a key role in intervention design and provision.

Recognising the dominance of Anglophone research in such a global field, particular efforts were made to invite authors from non-English-speaking countries to submit, and all the articles have abstracts available in French and Spanish alongside English.

Despite the endorsement of person-centred approaches by the WHO and in other guidance documents, in his commentary, Prof. David Molyneux highlights the way that this perspective is not currently built into how we measure need or define priorities.⁷ If Global Burden of Disease estimates properly acknowledged the mental health impact of different NTDs, there would be a far greater recognition of the real investment case for integrated care models that national NTD programs are being encouraged to implement. Science often follows social change, and this is the case for efforts to place people at the centre of NTD work. If the sector is to be fit for purpose in a public health agenda that demands universal health coverage, integrated care models and accountability to service users, the evidence needs to be there to know how to do this well. The authors in this supplement have produced valuable work to help realise this paradigm shift. There remain some gaps in the priorities set 5 y ago; understanding how mental health and stigma interventions impact on physical outcomes at an individual level and on elimination targets would help bridge the intersection between prevention and disease management. We are also yet to see sufficient research on how we can scale integrated services to reach the most marginalised (we are currently largely at the pilot stage) or the most effective means of supporting national NTD programs in the policy and financial frameworks that need to be in place.

We are grateful for the contribution that the authors and research participants have made to this supplement. This is a dynamic community with a strong commitment to see evidence brought into practice, and we received many submissions. A second upcoming section will develop these themes further. We hope these articles will provide inspiration and evidence for the change that global frameworks demand and which

many national actors in endemic countries are seeking to bring about.

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