



**COR-NTD 2020**

**Virtual Meeting, November 12 – 14**

**Integrating for Impact**

**Stigma Reduction and Mental Health Support for People Affected by NTDs**

**Session Date:** 11/13/20

**Session Time:** 9:00 AM - 12:00 PM EST

**Session Description:** This session will synthesize and build upon learnings from a series of pre-meeting sessions, which will focus on measuring the impact of NTDs on disability, morbidity, stigma and mental ill-health and addressing stigma and the mental health burden of NTDs.

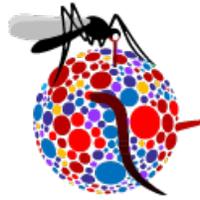
During this session we will:

- Facilitate understanding of, and dialogue around, mental wellbeing as related to different disease areas in diverse contexts.
- Provide an overview of the existing evidence base in relation to the measurement of burden associated with NTDs, disability, mental health and stigma
- Provide first-hand exposure to a chronic disease self-management intervention(s) that can be applied to diverse NTDs and chronic conditions.
- Promote discussion and formulation of outputs for furthering research to build the evidence base of effective mental health interventions that could be implemented at scale and sustained within NTD-affected populations.

Considering these areas are essential to develop a collaborative research agenda to support people-centered approaches in the World Health Organization's 2021-2030 Road Map for neglected tropical diseases.

**Session Chairs:** ICHORDS

**Session Rapporteur:** Helen Piotrowski



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## KEY DISCUSSION POINTS

*What key findings and data did the group identify via presentations? What issues were raised in discussions?*

- *'Mental Health and NTDS: What do we mean and how far have we come'. Presented by Julian Eaton*
  - During this presentation, Julian highlighted the psycho-social distress and social exclusion often experienced by those affected by NTDs. Julian proposed that the NTD agenda on elimination is moving quickly, and that it is possible to achieve this for mental health too.
  - Julian highlighted the progress already made around mental health and wellbeing since 2013, and the importance of person-centred approaches, highlighted most recently in WHO's new document 'Mental Health of people with neglected tropical diseases, towards a person-centred approach'.
  - A wide range of interventions are needed to support different needs of people with NTDs in relation to their mental wellbeing. This requires interventions that are responsive across the continuum of psycho-social distress, from common to more severe mental health conditions.
- *'Measuring the impact of NTDs on disability, morbidity, stigma and mental ill-health: what do we know, what tools do we have, and where do we go from here?'. Presented by Shahreen Chowdhury*
  - Shahreen reviewed four presentations provided within one of COR-NTD 2020 pre-sessions (title above). Learnings from these presentations include that there is a strong link between skin NTDs, stigma and mental wellbeing. Poor mental wellbeing includes depression, and internal or enacted stigma. Shahreen highlighted that research evidence is needed to highlight this as a priority for policy makers as mental health is often "invisible".
  - People affected by NTDs can be agents of change and should be included in the design and evaluation of interventions. Health workers perspectives should also be included.
  - There are a range of quantitative and qualitative tools which can be used to assess mental health in NTDs. Quantitative tools include different measurement scales, and qualitative tools can include participatory and creative visual methods, in depth interviews and focus group discussions (some examples of these can be found at [www.stigma-guides.org](http://www.stigma-guides.org)).
  - Shahreen suggested that there is a need for evaluation tools to enable gender disaggregated data to be collected. Tools can be adapted from other fields, or externally validated tools.



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- ‘Addressing Stigma and the Mental Health Burden of NTDs: Country Examples of Integrated Care’ presented by Sadie Bazur-Leidy
  - Stigma can impact on all areas of NTD control. Therefore, addressing mental wellbeing will not only improve people’s quality of life, but will also contribute to NTD elimination. Sadie highlighted the core themes, which include: Community and patient perspectives; Community based interventions have been shown to be affective in Haiti (Hope clubs), Nigeria (Hope groups), India (self-support groups) and Tanzania (community-based stigma-reduction); Sustainability and the need to work with local governments; and Partnerships to synergise with other organizations and stakeholders.

Following these presentations there was a comprehensive discussion on the barriers and facilitators to addressing stigma and mental wellbeing at different levels including with: people-affected, communities, health workers and at policy level, as well a discussion on what tools can be used to evaluate progress of interventions, and how best to integrate services.

#### **KNOWLEDGE GAPS IDENTIFIED**

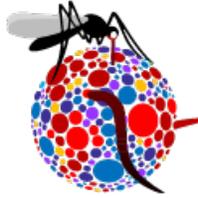
*What data and tools need to be generated to address the issues raised by the group?*

#### **People affected by NTDs and/or Mental Health should be involved in design, implementation, and evaluation of interventions:**

- It was important to look at wider elements of well-being, such as being able to work or not, and not just look at symptom improvement as a measure of success in programmes. Priorities should be determined with people affected, and can then be used as a baseline to measure interventions against
- There is a need to work with people affected to learn from their lived experience, and who can support treatment of others, advocate for change, and raise awareness
- Skills building can support building resilience and improve economic status, which can lead towards building a positive self-image.
- Self-stigma can be a barrier to seeking health care. Peer support groups can empower individuals, who can then go on to support others.

#### **Communities can play an important role in stigma interventions:**

- Benedict Dossen highlighted the important role communities had during Ebola to support mental health and reduce stigma. Trained community leaders and Community Health Workers can help identify and refer people, they have power and can therefore play a key role in reducing stigma. Involving community leaders is also really important to make sure that human rights are protected and there is understanding of what appropriate treatment for mental health is.



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- He highlighted that in Liberia, persons-affected by mental health have supported at the community level through:
  - Stigma and wellbeing awareness in the community which has led to advocating for policy change.
  - Supporting in peer mentoring and working with schools to raise awareness.
  - Supporting people and their families to re-integrate back into the community.
  - Working with the media to reach different communities to increase awareness

**Build the capacity of the health workforce to meet patients' needs:**

- Stigma amongst professionals may lead to higher stigma in the population. Therefore, there is a need to work with health professions on this and raise the profile of NTDs. Working with frontline health workers to dispel myths is important, however, it may be met with initial resistance.
- Health workers can become stressed if they don't feel they have the tools and capacity to support wellbeing, so supporting their wellbeing is also quite important.

**Scale up, Policy, Funding, and Integration:**

- Existing evidence should be used to leverage much-needed additional funding.
- Mental health and stigma interventions are becoming increasingly important, especially as PC-NTD programmes are phased out. Focus on sustainability and long-term benefits should also be used to leverage funds
- Poverty and long distances to health facilities means there is a delay in health-seeking behaviours, which means that health systems must reach out to marginalised communities.
- People often work in silos, and therefore may duplicate the process. There is a need to collaborate, make connections, and share tools.
- Specific conditions like onchocerciasis- associated epilepsy are often missed from disease management strategies. Audience participants expressed that there was a real opportunity to help tackle stigma around epilepsy, blindness, visual impairments, and skin diseases that can be associated with onchocerciasis through community based, patient focused mechanisms. Furthermore, WHO have just agreed guidance on epilepsy, therefore there is an opportunity to make sure mental health and stigma is included in this.

**Tools that are currently used to assess stigma and mental health in persons affected by NTDs include:**

- NTD Morbidity and Disability Toolkit (<https://www.infontd.org/ntd-morbidity-and-disability-nmd-toolkit>), which contains 15 tools
- The Participation Scale is part of the NMD Toolkit. This a generic instrument based on the WHO ICF measuring different aspects of work and social participants. It has been translated in 25+ languages and has been used in many different stigmatised conditions.



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- The SARI stigma scale is also included and was described as a comprehensive tool that assesses experienced stigma, anticipated stigma, internalised stigma and disclosure concerns
- SRQ (general mental distress) has been used in management of leprosy, Chagas and leishmaniasis, and with the WEMWBS (mental wellbeing), PHQ-9 (depression) used in the management of leprosy and LF.
- Guides on stigma and mental wellbeing (<https://www.infontd.org/toolkits/stigma-guides/stigmaguides>)
- Disability and Gender Toolkit from CBM Global ([shorturl.at/gpBN1](http://shorturl.at/gpBN1))

## **RECOMMENDED NEXT STEPS**

*What operational research and other actions need to be taken to address the knowledge gaps identified by the group?*

### **Operational research questions**

- How can we scale up the use of existing stigma reduction strategies within health systems?
- What measurement tools are most appropriate to evaluate stigma and stigma reduction innovations?
- How can we embed gendered experience of stigma in research?
- How can we better engage different stakeholders, such as community leaders, families and carers of people affected by NTDs, non-formal health providers, and formal health providers? What role will they contribute to stigma reduction strategies?
- How can collaboration between NTD programme managers and mental health providers be strengthened?
- How can we develop training packages for different levels of health system, for patients, and communities in order to improve knowledge and skills in stigma reduction and mental wellbeing?
- How can we include and/or increase the participation of people affected in research and intervention designs?
- How can we consider the mental wellbeing of health workers and how can we best build their capacity to support people affected by NTDs and provide mental health support?
- How can we safely involve volunteers in stigma reduction programmes? What are the techniques, opportunities, and challenges of using volunteers?
- How can inclusive livelihoods programmes be integrated with NTD mental health programmes?
- How can we assess the impact/effectiveness of stigma reduction interventions?



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**Actions/Next Steps**

1. Develop Educational packages for different levels including:
  - Communities
  - People affected by NTDs
  - Media
  - Health workers
2. Conduct a workshop to map and evaluate what tools are available and how they can be adapted and used appropriately
3. Embed initiatives, interventions, and innovations sustainably
4. Understand how drivers of social determinants can best be addressed
5. Strengthen evidence base and use this to leverage funding with donors