

Terms of Reference for the NNN Disease Management, Disability and Inclusion (DMDI) Working Group

THE DMDI APPROACH

Neglected Tropical Diseases (NTDs) lead to significant morbidity and chronic disability and trap individuals, their families and communities in a cycle of poverty. Their combined Disability Adjusted Life Years (DALYs) equal those of Malaria, TB or HIV/AIDS, and there is considerable evidence that they are significantly underestimated when other consequences, such as stigma and mental wellbeing, are taken into account. In addition to the crucial WHO-led global efforts in prevention and elimination, NTDs thus have distinct public health and patient care dimensions for those already affected. However, systematic consideration of “Disease Management, Disability and Inclusion” (DMDI) is lacking or relatively weak in most NTD programmes. Unfortunately, so far only a few NTDs, such as trachoma, LF and leprosy, have formally included the provision of basic care for individuals affected into their elimination goals.

DMDI recognizes and underpins WHO's promotion of NTDs as a proxy for poverty, marginalization and inequity under the WHO Road Map, the Sustainable Development Goals (SDGs) and Universal Health Coverage (UHC). The DMDI concept includes and actively supports Morbidity Management and Disability Prevention (MMDP) as one important component of the comprehensive “continuum of care” required by many persons affected by NTDs. The DMDI approach promotes equitable and inclusive quality patient care reflecting the cross-cutting features of NTDs. DMDI may be defined as “an approach that encompasses the medical treatment of NTD complications, the prevention and (self-)management of disabilities, promotion of mental wellbeing, reduction of stigma and promotion of other interventions and approaches that facilitate inclusion in society, such as human rights, participation of affected persons and communities, and livelihood”.

THE NNN CROSS-CUTTING DMDI WORKING GROUP

The NGO NTDs Network (NNN) cross-cutting working group on DMDI provides a unique and growing platform for engagement, shared learning, coordination, capacity development and advocacy for interested stakeholders. In this context, systematically coordinating and collaborating with the WHO NTDs-, Mental Health-, and related departments and initiatives is essential to achieve our common goals.

Objectives of the DMDI Working Group

- a) To promote a comprehensive continuum of care based on a social disability model, and position NTDs within the wider field of disability.
- b) To identify cross-cutting issues and interventions relevant across NTDs and develop strategies, tools, and technical and programmatic resources for capacity development of NTD programmes.
- c) To identify opportunities for information sharing and cross-learning between NTD actors, and facilitate access to up-to-date information regarding research findings, developments and innovations in NTD-related disability.
- d) To promote and facilitate implementation research on patient-centred intensive disease management, disability prevention, mental wellbeing, stigma reduction, participation of affected individuals and communities, inclusion and human rights.

- e) To advocate for scaling up the funding and implementation of available DMDI interventions across the spectrum of NTDs.

Operations of the DMDI working group

The DMDI working group operates through largely independent Task Groups (TG) as the principle platform for member engagement and work.

The DMDI working group meets face-to-face twice a year, once in the autumn as part of the annual NNN conference and once in spring.

Roles and Responsibilities

The three key roles within the executive group include the Chair, Vice-Chair and the Secretary. Collectively they will work together and share decision-making processes in the interests of the WG. Specific role definitions are as follows:

Executive Group (EG):

1. The Chair and Vice-Chair coordinate the day-to-day operations of the DMDI working group with support from the secretary
2. The Chair presents the DMDI working group's progress at the annual NNN meeting
3. The Chair represents the DMDI working group in NNN ExCo meetings and gives feedback to the DMDI working group from the NNN ExCo
4. The Chair, Vice-Chair and immediate-past Chair manage the DMDI working group membership including reviewing membership applications, inducting new members, and fostering membership engagement

Extended Leadership Group (ELG):

1. The ELG comprises the EG plus the Task Group Convenors
2. The ELG coordinates the development and execution of a work plan reflecting the purpose and scope of the DMDI working group
3. The ELG regularly reviews the tasks and progress of the DMDI working group and its task groups
4. The ELG plans, organises and facilitates DMDI working group meetings (twice a year - Spring and Autumn)

Secretary:

1. The secretary organises and facilitates meetings of the EG and ELG
2. The secretary takes minutes for meetings and supports the functioning of the EG and ELG
3. The secretary liaises with the convenors of task groups and facilitates their activities as required
4. The secretary ensures that the DMDI pages on InfoNTD are accurate and up-to-date in collaboration with the InfoNTD Information Officer
5. The secretary receives membership applications and forwards them to the Chair for review
6. The secretary communicates with DMDI Members and the NNN Communications officer as needed
7. The secretary manages the DMDI working group document sharing platforms

Version Tracking

Version and date	Comments
December 2016 Version 1	Submitted to NNN EC for endorsement (WvB)
November 2017 Version 2	Terminology updated to reflect change from MMDP to DMDI. (JE)
28 th FEB 2019 Version 3	We need to have a final EG-draft for discussion and adoption of a final version at the April 2019 spring meeting (BH/MK)