

Terms of Reference for the DMDI Working Group¹

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Purpose of the NNN DMDI Working Group (WG)

1. To promote the importance of patient-centred intensive disease management (PIDM), disability prevention (DP), stigma reduction and other relevant DMDI topics across the range of NTDs in the context of a comprehensive “continuum of care” approach.
2. To discuss the relevance of the UN CRPD and WHO ICF for DMDI; to discuss how to position NTD-related DMDI in the wider field of disability.
3. To make an inventory of/map the issues that exist regarding DMDI and the interventions needed and/or used for people affected by the different NTDs; to identify gaps that needs to be addressed.
4. To identify which issues and interventions are relevant for two or more NTDs (cross-cutting issues and interventions). To identify specific examples of these to serve as case studies.
5. To identify opportunities for information sharing and cross-learning between disease-specific work and/or geographic areas; to identify specific examples to serve as case studies if possible.
6. To facilitate access for relevant stakeholders and actors to up-to-date information regarding research findings, developments and innovations in the DMDI field.
7. To promote the development and use of evidence-based and/or best practices in the field of DMDI.
8. To promote and facilitate research on interventions for PIDM and DP; specific needs include implementation research, innovative interventions, cross-cutting interventions and cross-learning between NTDs.
9. To promote the implementation of available interventions for DMDI across the spectrum of NTDs.

Scope of engagement

The scope of the NNN DMDI WG is very broad and multi-sector, encompassing health, labour, education, agriculture, WASH, social welfare and human rights.

1. To liaise with the WHO and other relevant stakeholders to develop measurable joint indicators and monitoring frameworks for DMDI and NTDs.
2. To support the NNN disease specific coordination groups and others to establish clear strategies for patient-centred intensive disease management, disability prevention, stigma reduction, rehabilitation and disability-inclusive development, with specific attention for strategies that would be applicable across multiple NTDs.

¹ This terms of reference will be regularly reviewed by the Chair and Vice-chair and the NNN Executive Committee (EC). Amendments to the TOR are developed by the DMDI WG, proposed by its Chair and Vice-chair and endorsed by the NNN EC. Additional WG activities can be identified by the Chair and Vice-chair or the NNN EC as needed. Any proposed activities will be agreed by the NNN Chair and Vice-chair.

3. To stay informed of ongoing research and programmatic innovation and disseminate available opportunities to NNN members; and to identify opportunities for learning, research and innovation.
4. To evaluate the need for and support the development of capacity strengthening tools for NTD and DMDI stakeholders.
5. To identify linkages with the disability community outside the field of NTDs and develop opportunities to build relationships and encourage active engagement.
6. To represent the NNN at relevant global meetings. Depending on the nature and topic of these meetings, relevant experts may be asked to represent the DMDI WG.
7. To provide an update of DMDI sector activities to the annual NNN meeting.

Membership

- Chair and Vice-chair to be appointed by the NNN EC
- WG Coordinator appointed by the WG Chair and Vice-chair
- Representatives (one focal person each) from each Disease Specific Coordination Group (DSCG)
- Representatives from other expert partners for whom DMDI is a relevant issue
- Representative of the WASH WG
- Representatives of technical subgroups of the DMDI WG that deal with specific areas of work (yet to be defined)
- The WG aims to utilise NNN members' collective expertise and resources, to achieve the purpose and scope of engagement of the WG. There will be an open call for individual representatives to join the working group when it is established and then each year prior to the NNN to fill vacancies as they arise.
- The following attributes and criteria will apply to individual representatives:
 - Technical skills and experience to progress the focus areas of the working group, and
 - Willingness and support from individual's employer to enable them to contribute actively and on a voluntary basis without compensation.
- (New) members will be selected from among nominations or expressions of interest (EoI) submitted to the Chair or Vice-Chair for selection and approval. The NNN EC is informed of any new appointments to the working group. Nominations and EoI should indicate the interest and experience of the person and the commitment of their employer to supporting their participation in the working group.

Roles and responsibilities of the Chair, Vice-chair and Coordinator

1. To lead the development and execution of a work plan reflecting the purpose and scope of the WG
2. To appoint a WG Secretary to draft agendas and take and circulate minutes of meetings
3. To manage WG meetings including planning, organising and facilitating meetings
4. To regularly review the tasks and progress of the WG and update the NNN EC
5. To liaise with the Coordinators of technical subgroups of the WG, and coordinate their activities as relevant
6. To manage WG membership including reviewing membership applications, liaising with NNN EC, inducting new members, and fostering their engagement
7. To present the WG's progress at the annual NNN meeting and regular EC meetings
8. To participate in NNN EC meetings and update WG members on relevant discussions

Ways of working

1. The WG will prepare a multi-year results-based plan of action, from which annual plans will be derived.
2. The WG is not a decision making forum, except on technical issues related to the work of the WG itself. Other issues will be recommended to the NNN EC for consideration and endorsement.
3. The WG will actively engage and coordinate with any disease specific DMDI or related groups or focal persons.
4. The WG will work through specific Task Groups that work on specific topics within the scope of DMDI.
5. The WG will have a timetable of regular teleconferences/Skype to achieve identified outputs.
6. Face to face meetings will be linked to existing other meetings where possible. Additional communication amongst members will be done by email, LinkedIn forum or other electronic means.
7. Participation in meetings or activities of the WG, including by non-NNN members, is by invitation of the WG Vice-chairs for specific activities or initiatives.
8. There is an expectation of open discussion within the WG with collective responsibility for final WG outputs.
9. Minutes comprising a record of issues, updates and recommendations will be sent to the NNN EC at the earliest opportunity following any WG meeting.
10. It is recognised that the NNN does not have funded administrative or project coordination support or a budget to support WG meetings. Relevant activities will be undertaken on a voluntary basis and within the resources of the WG membership.

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)