

Summary from LF NGDO Survey April-May 2018

To better understand how the LF NGDO Network Group can move forward, work better together and contribute to the success of global elimination of LF, a brief survey to capture key information and opinions was circulated to the LF NGDO Network survey member list in April-May 2018. In total, there were 24 respondents from 19 organizations. A summary of results is presented below with selected notes from the Chair (blue text). Note all questions were optional, not all were answered.

Organisation/Institution represented

- AIM Initiative
- American Leprosy Missions
- CBM
- Consultant
- HDI (Health & Development Int'l)
- HKI
- IMA World Health
- International Podoconiosis Initiative
- Lepra
- Liverpool School of Tropical Medicine
- Malaria Consortium
- Mectizan Donation Program
- MITOSATH
- RTI
- Task Force for Global Health
- The Carter Center
- The END Fund
- The MENTOR Initiative (MENTOR)
- WHO

The theme for the next NNN is 'Reaching the last billion - setting BEST in motion' and there is a call for workshop proposals. Please indicate any ideas you have for workshops

These have been broadly grouped into themes.

MDA

- Working together to bridge MDA gaps in target communities
- Workshop on scale-up of Triple Drug (IDA) MDA
- Improving community participation during MDA through drama and public engagement
- Getting the coverage needed to stop MDA everywhere (cutting across all NTDs and important for LF)

MMDP

- Aligning MMDP with Universal Health Coverage
- Inclusion of basic care packages across NTDs within criteria for validation of disease elimination as a public health problem
- The impact of good self-care practices in increasing MDA and disease control compliance

- LF MMDP - how are LF programmes strengthening the health system and other sectors to provide patient care including domestic resource financing
- The participation of the person affected, their family and community in good care practices to sustain disease prevention and improve quality of life
- LF MMDP Workshop Training Modules, presentation of the tool and experiences using it to date
- LF MDDP component of the dossier, explanation of the WHO requirements
- Hydrocele surgery technical and programmatic updates

LF and Oncho

- Coordinating LF and Oncho for the endgame
- Coordinating Stop MDA in LF and RB in Africa
- [Oncho elimination surveys]
- [Reaching oncho elimination in hypo-endemic areas where Loa Loa is present]

Integration/ Health systems/ other programmes or diseases

- Inclusion of LF morbidity management into mainstream health systems
- Strengthening capacity in integrated vector management: suggested steps and indicators of success
- Integration into health system
- Integrating NTDs into HMIS and DHIS2
- Dealing LF and leprosy complication - a combined approach initiatives
- Integrated care for sustainable HS strengthening
- Strengthening country capacity

Challenges/Conflict

- Impossible to reach? NTDs in Conflict and Emergency Settings: Experiences, gaps and ways forward
- NTDs and refugees or areas of conflict
- Challenges in reaching the last billion in conflict settings

Future / Validation / Post 2020 / Sustainability

- Lessons from two decades of NTD control and setting up of priorities for next decade
- LF - What will be the target post-2020. How to deal with programme fatigue
- Validation of elimination of LF as a public health problem - country examples of achieving sustainable access to patient care and sustainable post-MDA surveillance
- Beyond Elimination - what capacity and support is there for national programmes after elimination

General

- Understanding the role of BEST in LF elimination
- The Missing. Who is missed, why, and what we can do about it. Quality assessment tools and how they can help
- NTDs and cross border situations
- LF "hotspots" and the way forward
- Research priorities
- STH - LF MDA cessation as elimination increases how is the STH treatment gap met
- [Considerations in re-defining STH goals]

What would you like to see presented at the LF NGDO group session? Or is there any particular topic or organization that you would like to see presented at the LF NGDO group session?

These have been broadly grouped into themes.

Advocacy /Partners/ NGDO Network

- Role of LF NGDO in GPELF and target countries
- Role of LF NGO community for the endgame
- In numbers, the contribution of the NGDOs to GPELF
- Role of LF NGDO in MMDP
- ESPEN Partner Mapping and GAP countries
- Raising the profile of LF for National Teams
- A strong emphasis/push for the NGDOs to support the MMDP components of LF elimination

MDA / TAS/ Transmission surveillance

- Urban MDA update
- Coverage survey updates
- Following up on LF positive cases identified in TAS 1 and TAS 2
- Defining steps from Pre-TAS to TAS
- Lessons learnt of countries in post-MDA surveillance phase on how they handle surveillance
- Conducting Pre-TAS/TAS in areas where oncho is still being treated
- Role of IVM and xenomonitoring in post MDA surveillance phase
- Lessons learnt of countries in post-MDA surveillance phase on how they handle surveillance
- Examples of sustainable, cost-effective post-MDA surveillance

MMDP

- Review and reflections on minimal package of care in LF
- Discussion on engaging government in provision of minimum MMDP package
- Morbidity management in low prevalence countries
- How have countries that have eliminated LF meaningfully reached the MMDP indicators in the dossier
- Update on IDM mapping for LF
- The impact of good self-care practices in increasing MDA and disease control compliance
- Updates on integrated MMDP
- Lymphoedema surveillance beyond ' LF elimination'
- Discussion on post-elimination LF patient management
- Peer Group Support for self care
- Overview of lymphatic system and key interventions used to reduce lymphoedema
- Integration of MMDP components across diseases

Strengthening programmes/ health systems

- Country examples of working with the health system to achieve sustainable patient care integrated into the health system
- Strengthening LF national elimination committees (lessons learned from existing ones, gap analysis, tools ...)

Future / Validation / Post 2020 / Sustainability

- Roadmap to Validation
- What does 'elim as a PH problem' really mean? verification vs validation
- Examples of activities to ensure sustainability
- Lessons learnt of countries in post-MDA surveillance phase on how they handle surveillance

- Ensuring the LF Dossier contains the needed information
- How to overcome PCT and DMDI gap for the endgame (sharing experience, lessons learned)
- Presentations from country programmes that have achieved LF elimination - I think this will help guide, motivate and inspire other LF programme managers

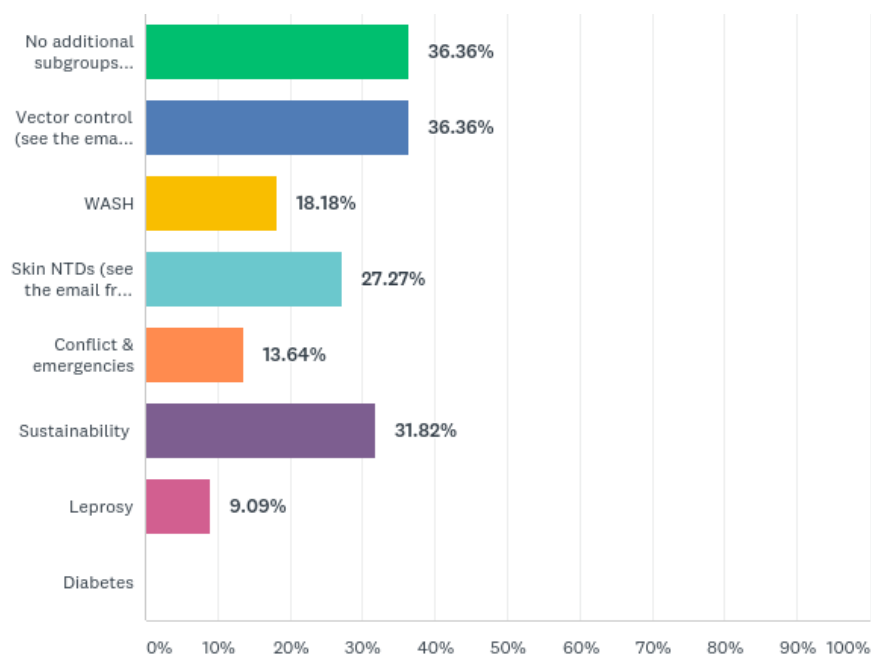
General / Research

- Research needs to demonstrate elimination of transmission
- LF & Livelihood initiatives

Do you think there should be other LF NGDO subgroups in addition to the existing LF/Oncho and MMDP/DMDI subgroups? (multiple options)

Overall, 8/22 (36.4%) respondents noted that there for no further subgroups with specific concerns raised about too many sub-groups becoming unmanageable, complicated to co-ordinate, and dilution of efforts. It was further suggested that there should not be LF subgroups but LF members systematically participating in the NNN cross cutting WGs.

Additional groups suggested included– Vector control (8), Sustainability (7), Skin NTD (6), WASH (4), Conflict & emergencies (3) and leprosy (2) (Figure below). The absence of gender was noted. Specific comments suggested that i) WASH, vector control and skin diseases should be addressed under a broader 'sustainability' working group - as we want to ensure that NTDs are embedded and sustained within these domains as opposed to recreate them within the NTD domain ii) In the DMDI sub group cross cutting issues could be included WASH, Skin NTDs, Leprosy, Chronic non-communicable diseases, mental health well-being and stigma reduction could be included.



Note from Chair: Based on the results, specific comments, lack of volunteers to lead sub-groups, complexity and cross-cutting nature of all sub-groups, there will be no additional sub-groups at this point in time. However, how information from the range of the other NNN groups can effectively feed into the LF NGDO sub-group will be put on the agenda for the next NNN meeting.

The LF NGDO member survey conducted in 2014 found that most members prefer the Chair to have a 2-year term (current TOR states one year). Do you agree with the change to 2 years?

In total 19/24 (79.2%) respondents preferred the Chair to have a 2-year term.

Note from the Chair: Based on the results, I will serve until 2019. However, as succession planning is important, we are still in need of a Vice Chair – therefore I will be calling for nominations.

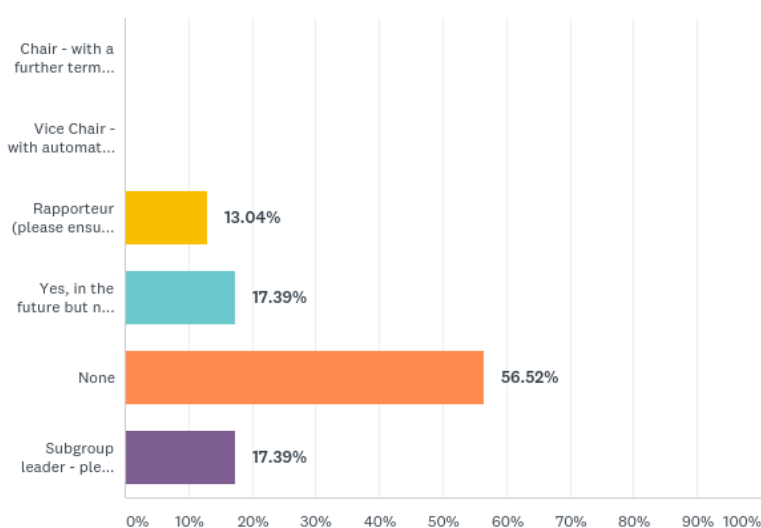
There is a new NNN London Declaration Scorecard Working Group being developed (see background in the email). Would you be willing to be the LF NGDO Network rep for this group?

In total 2/23 (8.7%) respondents would be willing to be the LF NGDO Network for this groups.

Note from the Chair: One of the two volunteers will be the new representatives and work with Molly Brady to ensure smooth handover and will be asked to present an update at the next NNN meeting.

The LF NGDO member survey conducted in 2014 found that succession planning is important to maintain momentum and continuity. Please select any position for which you would be willing to volunteer (multiple options)

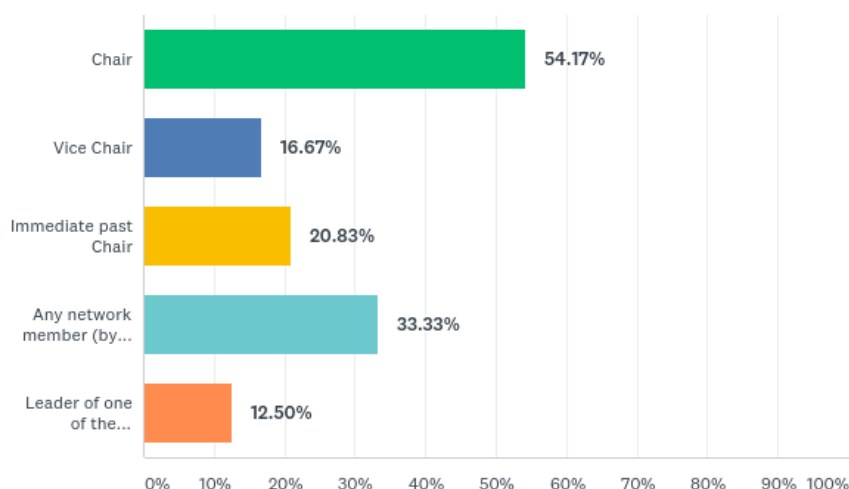
In total 13/23 (56.5%) respondents indicated that they could not help with any position, with some citing that they are already on other groups and have other committee commitments. Four respondents indicated they may be interested in a role in the future with some citing their short-term contracts a barrier to a longer-term commitment. Three respondents offered to be rapporteur for the next NNN meeting. In response to sub-groups leaders, two respondents indicated they could would be happy to be LF MMDP sub-group and one for Vector control if it was developed.



Note from the Chair: As succession planning is important, we are still in need of a Vice Chair – therefore I will be calling for nominations.

Who should be the LF NDGO Network's representative to ESPEN? (Enter as many options as you think appropriate)

In total 13/24 (54.2%) respondents indicated that the Chair should be the LF NDGO Network's representative to ESPEN, with others indicating the Vice Chair (4), Immediate Past Chair (5), any network member (8) or a leader of one of the sub-groups (3).



Note from the Chair: Based on the results, the Chair should be the representative. However, it has come to light that there are already elected NNN representatives for ESPEN (currently Yaobi Zang and Simon Bush), who cover all PC NTDs and will forward feedback to the LF Chair to pass to the LF NDGO group.

Do you prefer quarterly or bi-annual email updates?

In total 14/25 (56.0%) respondents prefer quarterly updates to biannual (32.0%), with a suggestion of adhoc periodical updates as necessary

Note from the Chair: Based on the results, the timing of the NNN meeting, brief updates will be circulated at the end of January & May ahead of the NNN meeting usually held in September.

Other comments

- Creating a map that puts everyone involved 'on the map' is a great initiative, but also a great motivation for the NGDOs and it increases visibility and creates partnership opportunities
- Important to demonstrate the huge contribution of the NGOs make to GPELF, have the NGOs report output (countries, treatments, surveys, diagnostics, burden assessments, workshops, surgeries, patients identified, financial resources invested etc..) this can be put into context by a total proportion of the reported GPELF output from the WER; the above should be presented at the GAELF; Secondly, by asking the NGOs to report on their work in a structured way, this will facilitate the coordination of work and expansion to fill gaps.
- Feedback from NNN and any other LF related meetings/events