



**TREAT-NMD Global Data systems Oversight Committee (TGDOC)
Disease Subgroup Leads
Terms of Reference**

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Terms of Reference

Role

The role of TGDOC Disease Subgroup Leads is to represent and support TGDOC Member Registries that collect patient data for that specific disease area. The Subgroup Leads will understand the capabilities and challenges of the TGDOC Registries that they represent and act as spokesperson(s) for them. They will encourage those registries that meet the TGDOC Core Member Registry criteria to maintain a quality Core Dataset and encourage/support those who meet TGDOC Affiliate Member Registry criteria to work towards becoming TGDOC Core Member Registries. The Subgroup Leads will also work with TREAT-NMD Disease Advisory Boards, in the development of new and Expanded Datasets as well as other related strategies and activities. The Subgroup Leads will liaise closely with the TGDOC Executive Board and TGDOC Member Registries, to help develop and maintain a high-quality Registry Network, and will act as TGDOC 'ambassadors' to promote TGDOC services and encourage new registries to join TGDOC.

Remit of the Subgroup Leads

Subgroup Leads will:

1. Coordinate the disease-specific subgroups via regular communication with Registry Curators,
2. Understand the capabilities and challenges of the TGDOC Registries that they represent and act as spokesperson(s) for them,
3. Encourage networking and collaboration within each disease area,
4. Arrange at least one subgroup meeting per year outside of the Annual Curators' meeting, with support from the TREAT-NMD Secretariat if required,
5. Encourage and support the TGDOC Membership process, including encouraging Affiliated Member Registries to become Core Member Registries when appropriate,
6. Promote and encourage new registries to join TGDOC,
7. Join the TGDOC Exec call to provide subgroup updates on a quarterly basis
8. Review and advise on new registry enquiries for their disease area,
9. Assist the TGDOC Exec Board with ensuring Core Member Registries participate in enquiry voting and data sharing,
10. Encourage, promote and support the new TGDOC Membership process,
11. Participate in TREAT-NMD Dataset development and update projects,
12. Oversee Patient Representative involvement with the subgroup,
13. Provide short written updates for inclusion in the quarterly TGDOC newsletters.

The chart below indicates which responsibilities are related to Core and Affiliated Member Registries:

Subgroup Lead Responsibilities	Core Members Subgroup (participate in enquiries)	Affiliated Members Subgroup (don't participate in enquiries)
Disease subgroups	Where TREAT-NMD Core Dataset exists	All NMDs
a) Assist with enquiry vote adherence	yes	n/a
b) Give advice in enquiry planning	yes	n/a
c) Assist with contacting new or unresponsive registries where necessary	yes	yes – also non-TGDOC registries
d) Support TGDOC Membership process	yes	yes – also non-TGDOC registries
e) Provide regular updates to TGDOC	yes	yes
f) Plan subgroup meetings	yes	yes
g) Support and encourage Affiliated members to become Core members	n/a	Yes – also non-TGDOC registries
h) Oversee Patient Representative involvement in TGDOC	yes	yes

Subgroup Lead Selection Criteria and rotation

- It is desirable that each disease subgroup for which a TREAT-NMD Core Dataset exists, should have two Subgroup Leads,
- Subgroup Leads will be selected by the TGDOC Exec Board and should be Core Member Registry Curators when possible,
- Subgroup Leads will serve a term of two years, but this may be extended by one year if agreed by the majority of the Registry Members in the subgroup,
- Where two Subgroup Leads are appointed to a Subgroup, their terms of service will be staggered to ensure continuity,
- Subgroup Leads wishing to step down from their role should inform the TGDOC Exec Board and provide as much notice as possible so a replacement can be found.

Meetings

- At least one Subgroup Lead from each disease area should attend the regular TGDOC Exec Board meeting on a quarterly basis, as arranged by the TREAT-NMD Secretariat.
- At least one Subgroup Lead from each disease area should attend and present an update at the TGDOC Annual Curators' meeting, which will include Subgroup networking time.
- At least one Subgroup meeting per year should be held (not including the TGDOC Annual Curators' meeting) with support from the TREAT-NMD Secretariat if required. These may be in-person meetings during a relevant conference for example, or virtual online meetings.
- Subgroup Leads may be asked to attend other TGDOC meetings as deemed appropriate by the TGDOC Executive Board.