**What is the MYONET registry?**

The MYONET registry is an international research and treatment database used by myositis specialists. It was created to collect uniform, longitudinal data from patients with myositis, to further our understanding of disease course and progression. Doctors from around the world are invited to join the collaboration and to record patient’s clinical details into the registry. The data can then be used either by the doctors at each base hospital, for clinical or research purposes, or by MYONET collaborators for research purposes.

**What patient data is collected within the registry?**

Data collected and recorded within the registry includes: The name of the base hospital and doctor, the patient’s ethnicity, month and year of birth, date of disease onset, diagnosis, clinical features, laboratory investigations, past and current medications, auto-antibody status and muscle biopsy details. Longitudinal data is also available for patients, including manual muscle testing, activity assessment, damage index, health assessment questionnaire, functionality index and quality of life index.

**Is patient data anonymised within the registry?**

All registry data is pseudonymised with patient’s names being replaced with study IDs. Each base hospital will maintain the link between study ID and patient name on separate password protected, encrypted, hospital computers. This is necessary to allow the doctors at each base hospital to keep track of which patients have been entered and to ensure follow up longitudinal data is entered under the correct study ID. However, any data released to collaborators (outside of the hospital) will be anonymised with a study ID linking all the clinical and demographic data.

**Is sample collection a requirement of joining the registry?**

No, sample collection is not a requirement for joining the registry. Historically, sample collection has been as part of the MYONET collaboration. However, the registry currently focuses on the collection of high quality, uniform, longitudinal patient data.

**Will I need Institute Review Board (IRB) approval to join the registry?**

Yes, you will need local IRB approval to join the registry and enter patient data. Additionally, you will need to sign a Data Sharing Agreement (DSA), to confirm sharing of registry data.

**How do I apply to join the registry?**

If you wish to join the registry, you will need to email the Chair of the MYONET Steering Committee (MSC), Professor Hector Chinoy, with an expression of interest. You should attach a 1-page summary, outlining your areas of interest in myositis and details of your patient cohort, along with a copy of your 1-page mini-CV.

Email: [hector.chinoy@manchester.ac.uk](mailto:hector.chinoy@manchester.ac.uk)

Your expression of interest will then be circulated to the MSC for consideration, and you will receive email notification of their decision within 10 working days of your application. If it is approved, you will need to ensure you have:

1. Local Institute Review Board (IRB) approval, to enter registry data.
2. A Data Sharing Agreement (DSA), to allow for sharing of registry data with collaborators.

Once IRB approval has been confirmed and the DSA signed, you will be given access to the registry. This will be via a link with login details, that allows you access to your own hospital’s data only. Your details will then be added to the ‘MYONET members list’ and registry entry can commence.

**Will I need Institute Review Board (IRB) approval to access registry data?**

If you (or your institute) are not MYONET members, you will need to ensure you have:

1. Local Institute Review Board (IRB) approval for your project.
2. A Data Sharing Agreement (DSA) to allow for transfer of registry data

However, if you are already a MYONET member, you will not require any further regulatory approvals to access registry data for research purposes (as you will already have IRB approval and a signed DSA in place).

**How do I apply to access registry data?**

If you wish to access registry data for your research project, you will need to email the Chair of the MYONET Steering Committee (MSC), Professor Hector Chinoy, with your request. You should attach a copy of the completed ‘Project Application Form’ - Outlining details of your project, and the specific data you require, along with a copy of your 1-page mini-CV. The Project Application Form will be provided by the MSC Chair upon request.

Your request to access registry data will then be circulated to the MSC for consideration, and you will receive email notification of their decision within 10 working days of your request. If it is approved, you will then need to sign a ‘Project Collaboration Agreement’ confirming terms and conditions, before being issued with a ‘Project Approval Letter’

Arrangements can then be made for the required data to be downloaded from the registry and made available to you and your institute.