MTM Registry Consent – For Deceased Patients

Myotubular and Centronuclear Myopathy (MTM and CNM) Patient Registry

Principal Investigator/Data Controller: Dr Chiara Marini Bettolo, Translational and Clinical Research Institute, Newcastle University

	PLEASE NOW READ THE CONSENT STATEMENTS BELOW AND GIVE YOUR CONSENT BYTICKING THE BOX NEXT TO EACH STATEMENT.	Tick box
1.	I confirm that I have read, and that I understand the above patient information (dated September 2021, version 2) for registering a deceased patient in the MTM and CNM Patient Registry. I have had the opportunity to consider the information and to ask questions.	
2.	I give consent for my family member's data to be stored in the MTM and CNM Registry and for it to be extracted (in anonymous form only identifiable by a code) so it may be used for research and for the planning of clinical trials.	
3.	I agree to be contacted as needed about the management of my online account, or my family member's data.	
4.	I give consent for the MTM and CNM Registry team to obtain access to relevant parts of my family member's medical records (if needed) to confirm their diagnosis, including genetic test results, muscle biopsy results, and related correspondence.	
5.	I understand that participation in this registry is voluntary and that I am free to withdraw my family member's data from the registry at any time, without giving any reason.	
6.	The nature of the registry has been fully explained to me. I have understood the patient information and I agree for my family member's data to be included in this registry.	

MTM and CNM Registry, Informed Consent for Family Members of Deceased Patients
Version 2
1st September 2021