

MTM Registry Consent - For Deceased Patients

Myotubular and Centronuclear Myopathy (MTM and CNM) Patient Registry

Principal Investigator: Dr Chiara Marini Bettolo, Newcastle University and Newcastle Hospitals
NHS Foundation Trust

Data Controller: Newcastle University

	<p>PLEASE NOW READ THE CONSENT STATEMENTS BELOW AND GIVE YOUR CONSENT BY TICKING THE BOX NEXT TO EACH STATEMENT.</p>	<p>Tick box</p>
1.	<p>I confirm that I have read, and that I understand the above patient information (dated December 2021, version 2.1) 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.</p>	
2.	<p>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.</p>	
3.	<p>I agree to be contacted as needed about the management of my online account, or my family member's data.</p>	
4.	<p>I give consent for the MTM and CNM Registry team to contact my nominated doctor or clinic (if needed) to request confirmation of my family member's diagnosis; for example a genetic test or muscle biopsy result.</p>	
5.	<p>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.</p>	
6.	<p>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.</p>	