

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

Informed Consent for Parents

	PLEASE NOW READ THE CONSENT STATEMENTS BELOW AND GIVE YOUR CONSENT BY TICKING THE BOX NEXT TO EACH STATEMENT. If you wish, your child may also give their assent by agreeing to the statements underneath their information below. This is optional.	Tick box
1.	I confirm that I have read, and that I understand the above patient information for parents (dated December 2021, version 2.1) for 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 child'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 understand that allowing my child's data to be stored on the registry does not mean my child will automatically be entered into future clinical trials.	
4.	I agree to be contacted periodically to provide an update about any changes in my child's medical condition, or about the management of my online account.	
5.	I understand that the registry will send me information about relevant clinical trials, studies or surveys, to support research into my child's disease.	
6.	I give consent for the MTM and CNM Registry team to contact my nominated doctor or clinic (if needed) to request confirmation of my child's diagnosis; for example a genetic test or muscle biopsy result.	
7.	I understand that the results from future research may not have any direct implications for my child or my family.	
8.	I understand that participation in this registry is voluntary and that I am free to withdraw my child's data at any time, without giving any reason, and without my child's medical care or legal rights being affected.	
9.	The nature of the registry has been fully explained to me. I have understood the patient information and I agree for my child to participate in this registry.	