

Myotubular and Centronuclear Myopathy Patient Registry

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NHS Foundation Trust

Data Controller: Newcastle University

Assent for children under the age of 16

		Tick box
1.	I confirm that I have read/had read to me and that I understand the patient information above (dated December 2021, version 2.1) for the MTM and CNM Patient Registry. I have had the opportunity to consider the information, to ask questions, and I have had these answered in a way that I understand.	
2.	I give consent for my data to be stored in the MTM and CNM Registry, and for it to be shared (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 data to be stored on the registry does not mean I will automatically be entered into future clinical trials.	
4.	I agree to be contacted occasionally to provide an update about any changes in my medical condition or about the management of my online account.	
5.	I give consent for the MTM and CNM Registry team to contact my nominated doctor or clinic (if needed) to request confirmation of my diagnosis; for example a genetic test or muscle biopsy result.	
6.	I understand that the results from future research may not have any direct benefit to me.	
7.	I understand that I may ask for my details to be removed from this registry at any time, without giving any reason, and without my medical care or legal rights being affected.	
8.	I understand that the registry will send me information about relevant clinical trials, studies, or surveys to support research into my disease.	
9.	The nature of this registry has been fully explained to me. I have understood the patient information and I agree to participate in the registry.	