# TEAM CONTACT DETAILS (alphabetical order)

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| **PARTNER** | **NAME** | **ROLE** |
| **Newcastle University – Institute of Neurosciences**  | Alasdair Blain | Statistician In site |
| **Utrecht University** | Ardine de Wit | Work Package (Academic) Lead |
| **Newcastle University – Institute of Neurosciences****And** **Evidera – Patient Centred Research Department** | Aura Cecilia Jimenez-Moreno | Study Project Manager |
| **Janssen R&D** | Bennett Levitan | Patient Preference expertise – study advisor |
| **Mito Canada** | Blaine Penny | Patient organisation lead |
| **Merck & Co.**  | Cathy Anne Pinto | Work Package (Industry) Lead |
| **Erasmus University Rotterdam** | Chiara Whichello | Methods expertise – lead of the Q-sort tool |
| **Newcastle University - Institute of Neurosciences** | Christine Dyer | Project Coordinator |
| **Muscular Dystrophy Canada** | Daria Wojtal and Barbara Stead-Coyle | Patient organisation lead |
| **KUL** | Eline van Overbeeke | Methods expertise – qualitative study lead |
| **Patient Representative and Cure DM**  | Emma-Jayne Ashley | Caregiver representation |
| **Erasmus University Rotterdam** | Esther W. de Bekker-Grob | Methods expertise leader & lead of the DCE tool |
| **Newcastle University – Institute of Neurosciences** | Grainne Gorman | Study Principal Investigator |
| **Utrecht University** | Ian Smith | Methods expertise – data analysis support |
| **Patient Representative** | James Ormrod | Caregiver representation |
| **Uppsala University** | Jennifer Viberg | Methods expertise and out of site statistician |
| **Muscular Dystrophy UK (MDUK)**  | Jenny Sharpe | Patient organisation lead and lead of patient engagement and communication. |
|  **Newcastle University – Institute of Neurosciences**  | Julie Murphy | Patient Engagement support  |
| **Patient Representative** | Kate Charlton | Patient representation |
| **Lilly** | Kristin Bullock | Patient communication and study dissemination |
| **Newcastle University – Institute of Neurosciences**  | Laura Brown | Study coordinator and ethics submission |
| **Muscular Dystrophy Association (MDA)** | Lianna Orlando | Patient organisation lead |
| **Newcastle University – Institute of Neurosciences** **and****Lily Foundation** | Lyndsey Craven-Butterworth | Patient Engagement support  |
| **Muscular Dystrophy New Zealand** | Miriam Rodrigues | Patient organisation lead |
| **Myotonic Dystrophy Foundation** | Molly White | Patient organisation lead |
| **United Mitochondrial Disease Foundation (UMDF)** | Philip Yeske | Patient organisation lead |
| **Newcastle University – Institute of Neurosciences** | Prof. Robert McFarland | Clinical expertise  |
| **Patient Representative** | Rachel Ward | Patient representation |
| **Erasmus University Rotterdam** | Vikas Soekhai | Methods expertise - led of the BWS2 tool |
| **The Newcastle upon Tyne Hospitals NHS Foundation Trust** | Jane Newman | Clinical expertise |