Maximizing the Synergy of Multidisciplinary Care for Duchenne Muscular Dystrophy (DMD) Patients in Wales

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Context and Approach:

Duchenne Muscular Dystrophy (DMD) is a progressive, debilitating and fatal neuromuscular disease. Due to the multisystem nature of the disease, robust multidisciplinary care approach is essential to meet the complex care needs of these frail and vulnerable patients. From our clinical experience, we realize there are certain areas of care that need improvement for DMD patients in Wales, in comparison to national recommendations. This study is to find out if our local care pathway is in line with national recommendations and if not, to identify the areas that need improvement for better resource relocation.

Progress to date:

Research:

The project is completed. The abstract is accepted, and I presented the project at the Association of British Neurologists Annual Conference in Liverpool on 8th May 2025. The abstract will be published in the Journal of Neurology, Neurosurgery & Psychiatry in the summer of 2025.

Leadership:

Through leading this project, I have empowered members of the project team to develop projects of their own. Examples include a specialist nurse from South-west neuromuscular team who is planning to develop a pathway/ guidelines for bone health together with an endocrinologist, and members from Rare Disease Implementation Network are trying to replicate the success of the physiotherapy service in Hywel Dda in other areas of Wales.

Education/teaching:

To raise the profile of rare diseases like DMD, I am also leading an educational project to assess the learning needs of rare diseases among Cardiff medical students. Data collection was completed in June 2024, and the date is now being analysed. I also co-led a rare disease teaching event for Swansea University medical students and junior doctors from Morriston Hospital on 8th March 2025 which was well received by students, rare disease charities and attending doctors.

Future activity:

To continue to raise the profile of rare diseases and advocate for such patients with significant unmet need. I am going for out of programme for a year to do a fellowship in Oxford, with the aim to do a higher degree in rare neuromuscular disorders. The ultimate goal is to bring something back to Wales and build a service for rare neuromuscular disorder patients.

Reflections:

- Data collection for North Wales cohort is particularly difficult due to governance preventing flow of data.
- I left NHS Wales as of 1 August 2024 for a training role in West Midlands. This prevented me from completing 2nd part of the project, which is to address the deficiencies we found and re-audit. However, this project has initiated conversations regarding rare disease care in Wales and the future of them.

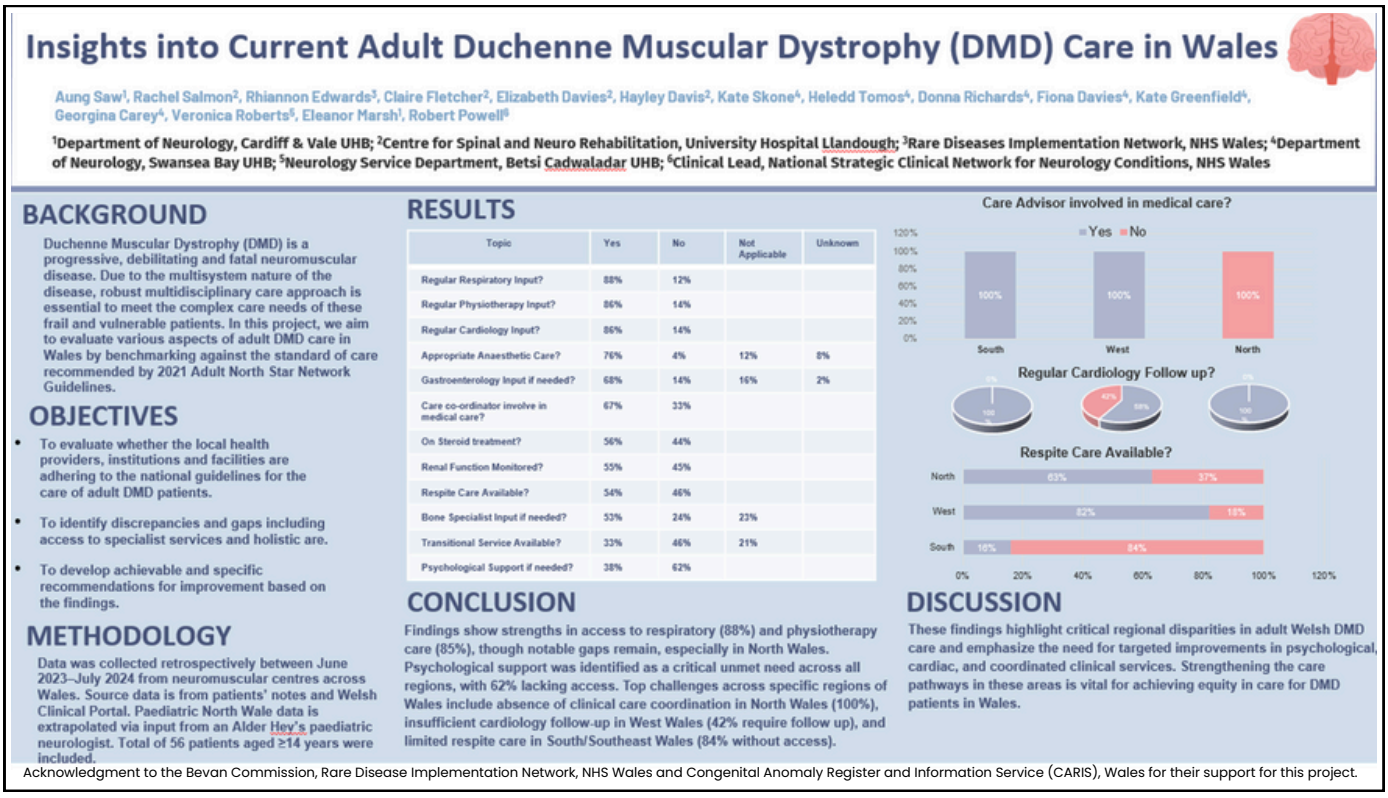

Figure 1: Poster presented at Association of British Neurologists Annual Conference