

Optimising patient pathways. Instigation of Southampton Children's Hospital (SCH) regional Neuromuscular (NM) Service, Allied Health Professional (AHP) clinic for Children and Young People (CYP) with Charcot Marie Tooth disease (CMT)



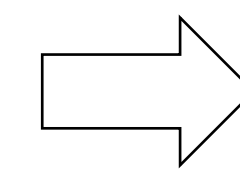
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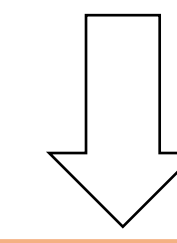


Background:

- Recent advances and therapies within neuromuscular care have led to an increased demand on SCH specialist neuromuscular services impacting on clinic availability, capacity, and timely access to the multidisciplinary team (MDT).
- A service review was required to ensure optimal patient care and address issues of increasing caseloads and service limitations.
- Conditions with limited medical management options were identified, including CMT. CMT is a genetic condition that damages the peripheral nerves. Key interventions are based on symptom management/functional considerations to increase independence and quality of life. Recognition of this and acknowledgment of the AHP skill set meant this cohort was proposed for alternative options to standard medical lead clinic.

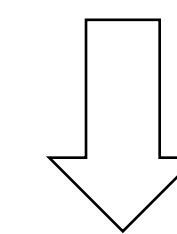


Aim: To ascertain the viability and instigation of an AHP led CMT clinic.



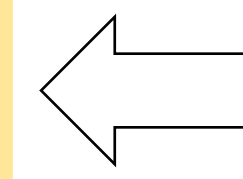
Methods:

- Dataset of CYP with CMT cohort identified.
- Individual patients with ongoing medical needs identified and exclusion criteria created.
- Eligible patient numbers reviewed.
- Patient pathway formalised.
- Identification of clinics required, and instigation commenced.
- Physiotherapist, Occupational Therapist and Specialist Nurse review of clinical capacity.



Results:

- 27 eligible patients were identified requiring 9 AHP clinics a year.
- Ability to offer more flexible and reduced length of wait for follow up from 12 to 9 months.
- Release 35 combined consultant lead MDT clinic slots a year increasing capacity for new patients or follow ups.
- Physiotherapist, Occupational Therapist and Specialist Nurse review had clinical capacity to accommodate clinic.



Conclusion:

- AHP CMT clinic concluded to be viable with potential benefits to service users and the wider NM service.
- Sufficient patient numbers were identified to warrant cohorted clinic.
- Ongoing review to ensure clinic meets needs of service users and clinicians with data collection to monitor satisfaction, holistic intervention, clinical governance compliance and timely actioning of onward referrals.
- Clinic established in May 2023.

Initial feedback:

"Maybe make the room a little more interesting for kids. The specialist were very friendly and put my daughter to ease quickly. The idea of a specialist team is excellent and will hopefully ease the NHS work-load. We have come out with some great advice and do-able exercises."

"Excellent service with incredibly knowledgeable staff. Listened extremely carefully to our needs and offered excellent support"

References:

1. Charcot-Marie-Tooth UK. (2018). *Health Professionals*. [Online]. Charcot-Marie-Tooth UK. Available at: <https://www.cmt.org.uk/health-professionals/> [Accessed 30th August 2023].
2. NHS. (2022). *Overview -Charcot-Marie-Tooth disease*. [Online]. www.nhs.uk. Available at: <https://www.nhs.uk/conditions/charcot-marie-tooth-disease/> [Accessed 30th August 2023].

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