

POSTER ABSTRACT

Co-designing an Integrated Care Pathway for Children and Families with a Neuromuscular Disorder in Ireland

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Margaret Rafferty¹, Grace Turner¹, Andrea Tobin²

1: HSE, Ireland;

2: Children's Neuromuscular Service at CRC and AMNCH, Ireland

Introduction: Children, adolescents and their families with a suspected or confirmed diagnosis of a neuromuscular disorder NMD require access to a broad range of healthcare services and supports in the community and acute hospital, from a range of different providers and agencies at any given point in time, due to the complexity of their condition. A neuromuscular disorder is a rare disease which is complex and progressive, often affecting multiple body systems. Neuromuscular disorders are often the result of genetic mistakes or mutations that affect muscle stability, the ability of muscle to regenerate or interrupt the communication between nerves and muscles. Examples of neuromuscular disorders include; Duchenne Muscular Dystrophy DMD, Congenital Muscular Dystrophy CMA and Spinal Muscular Atrophy SMA.

Context: While clinical pathways exist for some children with NMD, they relate to children with a specific diagnosis, different points in the child's care journey, or areas of specific clinical management. No integrated care pathway exists to capture the entire care journey, to give guidance to service providers with regard to delivering standardised, child and family centred, integrated care.

Targetted objective: The objective of the project, established by the Integrated Care Program for Children, is to standardise the care journey of a child with NMD and their family from initial presentation and diagnosis to transition to adult services through the co-design and implementation of an Integrated Care Pathway with parents, young adults with NMD and healthcare providers. The pathway focuses on standardisation and integration of services and, critically, on how services communicate with children and families themselves, and with each other.

Highlights:

Innovations: Focus groups and telephone interviews were conducted with parents and young adults with NMD in relation to their personal experience of services and their perspective on how services could be improved. A multidisciplinary steering group was established which included a consultant neurologist as clinical lead and two parent representatives. A project group and patient reference group were established to ensure a collaborative model of design was applied throughout.

Impacts: Three distinct phases emerged during the co-design stage: Phase One: Recognition and/or Diagnosis, Phase Two: On-going Care and Phase Three: Transition. Within each phase a number of themes were agreed, and a specific set of standards was developed for each theme. A suite of practical family resources have also been co- designed as part of the pathway to help meet the agreed standards. Further resources have been identified for co-design in 2018.

Outcomes: Co-design and formal consultation stages of the pathway are complete. The pathway is now going through a formal approval process. Launch of the integrated care pathway is planned for early 2018. The pathway will be tested in two geographical areas in 2018, prior to phased national implementation.

Learning & transferability: The project gives a unique insight into the needs and priorities of children and families with neuromuscular disorders and has provided an opportunity to co-design what families feel will meet their needs. This learning could be applied to children with a range of diagnoses over time.

Keywords: co-design; integrated care pathway; children and families; neuromuscular disorders
