Canadian MSK Rehab Research

From Partnership to Practice: Co-Developing and Mobilizing Rehabilitation Recommendations for People with Lived and Professional Experience



We wanted to know

What is known about effective rehabilitation for children with AMC across key areas, including early intervention and motor development, muscle and joint function, orthotics, mobility, participation in everyday life, pain, psychosocial well-being, and rehabilitation before and after surgery?

What is the problem?

Arthrogryposis multiplex congenita (AMC) is a rare condition that causes joint stiffness and contractures, muscle weakness, and difficulties with movement and everyday activities. Families may have difficulty finding healthcare professionals with specialized knowledge, travel long distances to access appropriate care, adding financial costs and emotional stress.

How did you study the problem?

To address this gap, healthcare professionals, researchers, people living with AMC, and caregivers worked together to develop rehabilitation recommendations. Importantly, people with lived experience and caregivers were actively involved in creating these recommendations to ensure that they reflected the needs and experiences of the AMC community.

What did you find?

The team developed rehabilitation recommendations with input from people with AMC and caregivers, bringing together professional expertise and lived experience. The work also focused on developing online learning modules and other educational resources to communicate these recommendations to healthcare professionals, individuals with AMC, caregivers, and other audiences. We found that including people with lived experience helped ensure that the recommendations and resources considered the needs and perspectives of the AMC community.

How can this research be used?

By bringing together professional knowledge and lived experience, this work aims to create rehabilitation resources that are relevant, trustworthy, and practical for people with AMC and their families. Not only that, but our methods can be used for creating recommendations for other rare diseases as well.

Cautions

AMC affects each person differently, and access to rehabilitation services and specialized expertise varies. Although the recommendations and educational resources have been developed to address gaps in care, further evaluation is needed to determine how well the resources reach their intended audiences, how useful they are in practice, and whether they improve rehabilitation care or outcomes for people with AMC.

Reference: Dahan-Oliel, N., Cachecho, S., Araujo, C., Fąfara, A., Lacombe, F., Samargian, A., Costa, C., Donohoe, M., Flanagan, A., Kowalczyk, B., Krakie, C., Wagner, L., Navalón, C., Pacey, V., Steen, U., Walker, M., Wong, T., & Bussières, A. (2025). Consensus-based recommendations for the rehabilitation of children with arthrogryposis multiplex congenita: an integrated knowledge translation approach. Orphanet journal of rare diseases, 20(1), 168. https://doi.org/10.1186/s13023-025-03671-x

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