

# Rehabilitation recommendations for arthrogryposis: Co-development, dissemination and implementation

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## Introduction

### Arthrogryposis Multiplex Congenita (AMC)

- ❑ Rare condition with multiple congenital contractures (~1 in 3,000 births).
- ❑ Affects limbs, spine, and jaw.
- ❑ Limits mobility, daily activities, and independence.



### Why rehabilitation matters

- ❑ Critical for early intervention.
- ❑ Maximizes movement, strength, and autonomy.
- ❑ A need to develop rehabilitation guidelines was expressed by people with AMC, their caregivers and experts in AMC.



## Objective

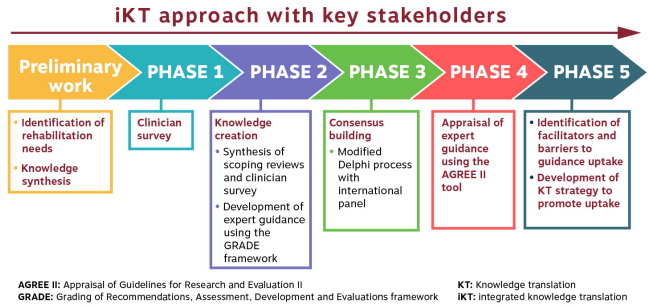
- ❑ Co-develop, disseminate, and implement rehabilitation recommendations for children with AMC.

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# Methods

## Co-development approach

- ❑ International, multidisciplinary expert group.
- ❑ Rehabilitation, orthopedics, plastic surgery, neurology, Kinesiology, social work & people with lived and living experience.



## Process

- ❑ Priority areas identified by children with AMC, caregivers, and clinicians.
- ❑ Consensus-based recommendations.

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### RESEARCH

### Open Access

## Consensus-based recommendations for the rehabilitation of children with arthrogryposis multiplex congenita: an integrated knowledge translation approach

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## Knowledge translation

- ❑ E-learning modules.
- ❑ Workshops and discussions to gather insights on feasibility of our information sharing approach from people with lived experience.
- ❑ Ensure the use of appropriate methods to reach necessary audiences.
- ❑ Pilot testing before broad dissemination.

# Practice Implications & Contribution to OT

## Practice implications

16 recommendations developed across:

- Early intervention
- Mobility training & assistive equipment
- Orthotics
- Peri-operative rehabilitation
- Participation
- Pain management
- Psychosocial well-being

## Contribution to Occupational Therapy

- Empowers clinicians, families, and people with lived experience.
- Supports advocacy and evidence-based, family-centered care.



Photo credit: Shriners Children's Greenville