



Shriners Hospitals
for Children® — Canada

From Consensus to Care: Co-Developing Rehabilitation Resources for Arthrogryposis Multiplex Congenita

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INTRODUCTION

Arthrogryposis multiplex congenita (AMC) is a group of rare musculoskeletal conditions characterized by:

- Multiple joint contractures at birth
- Reduced mobility
- Muscle weakness
- Functional limitations across the lifespan

Rehabilitation is essential throughout life. However:

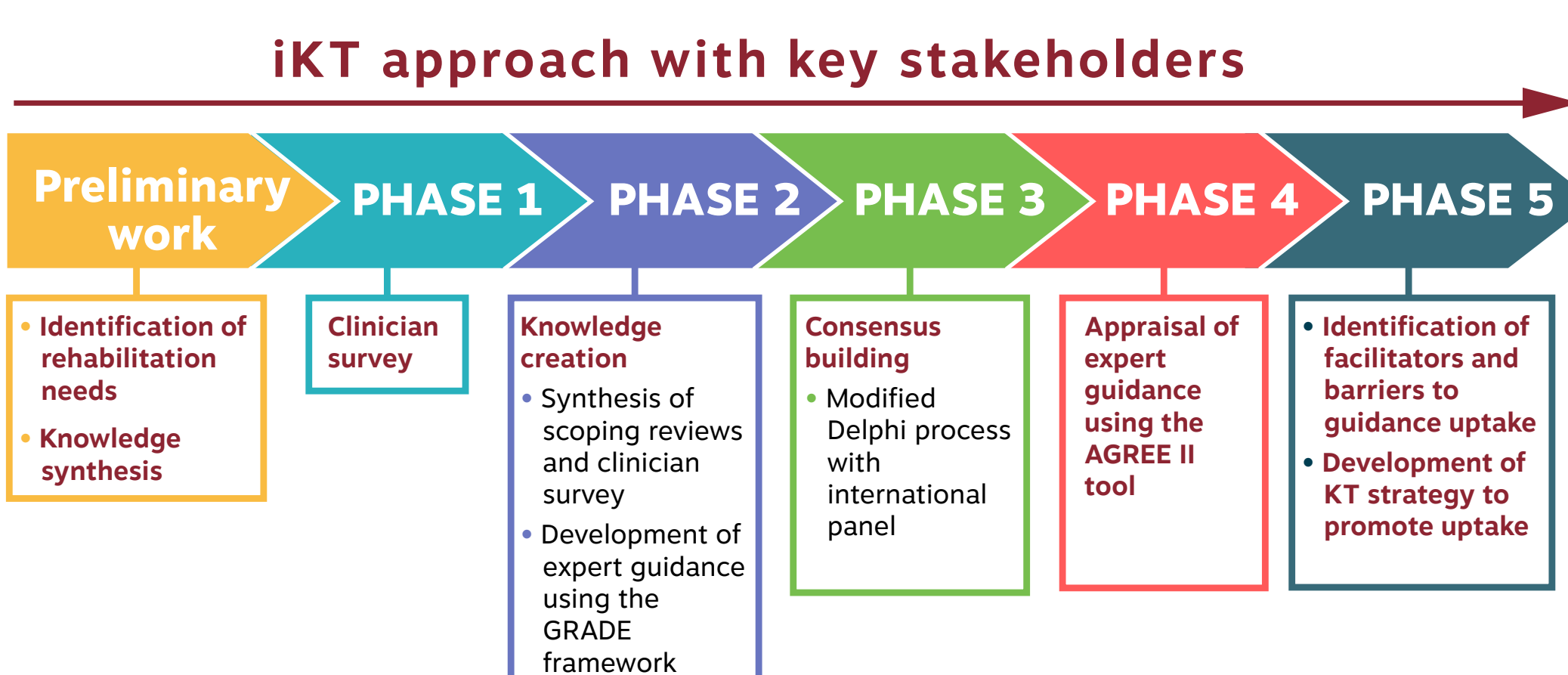
- AMC is rare and heterogeneous
- Access to specialized programs is limited
- Families often travel long distances
- Financial and caregiver burden is substantial

Development of consensus-based rehabilitation recommendations

Using a participatory, co-development model with a multidisciplinary international working group, including:

- Rehabilitation clinicians (physical therapists, occupational therapists)
- Developmental pediatricians
- Neurologists
- Physiatrists
- Orthotists
- Researchers with expertise in AMC
- Individuals with AMC
- Caregivers

16 recommendations in 8 domains



AGREE II: Appraisal of Guidelines for Research and Evaluation II
GRADE: Grading of Recommendations, Assessment, Development and Evaluations framework

KT: Knowledge translation
iKT: integrated knowledge translation

Although international consensus-based rehabilitation recommendations exist, effective implementation requires strategic dissemination.

OBJECTIVES

1. Establish a **sustainable partnership** between clinicians, researchers, and individuals with lived experience
2. Co-develop and validate **e-learning modules** on rehabilitation recommendations
3. Create and disseminate **tailored knowledge mobilization products** for priority audiences

METHODS

Team Composition (Canada (n=14), USA (n=1), Spain (n=1))

- Rehabilitation specialists (n=1)
- Developmental pediatricians (n=1)
- Neurologists (n=1)
- Physiatrists (n=1)
- Orthotists (n=1, and lived experience)
- Researchers (n=6)
- Caregivers/Individuals with AMC (n=6)



Process

- Monthly virtual meetings
- Small group working sessions
- National & international presentations
- Iterative review of e-learning modules

RESULTS

Review of e-learning modules for:

- Accuracy
- Clarity
- Relevance
- Accessibility
- Usability

Lived Experience Strengthened the Work by:

- Refining language and tone (e.g. personal voice-over)
- Improving accessibility (visuals, glossary, special video formats)
- Enhancing clarity and usability (accessibility of platform)
- Optimizing format and delivery (CME credits)

Tailored Dissemination Products

Key Audiences	Examples of Dissemination Products
Caregivers	Colouring book, educational sessions/presentations with community organizations (AMCSI, Muscular Dystrophy Canada)
Rehabilitation professionals	Conferences, Infographic, Podcast
Physicians (general practitioners and specialists involved in the care of children with AMC)	Conferences at local and international events (rare diseases, bone disorders, pediatric neurology)

CONCLUSION

This project:

- Addresses a critical gap in AMC rehabilitation care
- Delivers the first co-developed rehabilitation recommendations and educational resources
- Enhances relevance, trust, and real-world applicability
- Provides a replicable and scalable model for integrating lived experience into:
 - Rare disease research
 - Guideline development
 - Knowledge mobilization



Funded by a Team Development Support from the Canadian MSK Rehab Research Network

References

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