

# GrowDMD: an International Study on Transition of Youth with Duchenne Muscular Dystrophy (DMD)

Comparing patient experiences and systems to optimize care



PRESENTER:  
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## BACKGROUND

- Duchenne muscular dystrophy (DMD) is a rare X-linked disease characterized by progressive muscle degeneration resulting in loss of ambulation and severe multisystem complications. Due to improvements in medical management some individuals with DMD now live beyond their third or fourth decade of life.
- Care pathways for transition from childhood to adulthood is a well-described phenomenon, however, organizational, cultural, administrative or policy barriers make it challenging to realize the guidelines into practice.
- While transition of care for patients with DMD is outlined in the International Care Considerations for DMD<sup>1</sup>, it is still neither well-described nor defined and organized at international level with common and agreed pathways and indicators.

## RESEARCH QUESTIONS

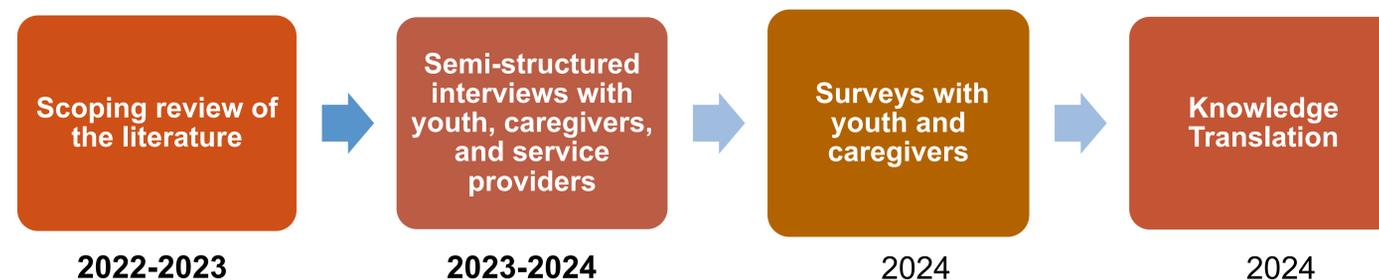
- How do patients with DMD and their caregivers experience the transition of care?
- What measures and strategies are currently implemented in the care organizations of participating countries to support and facilitate the transition of care?
- How can the transition of care be improved?

## THEORETICAL FRAMEWORK

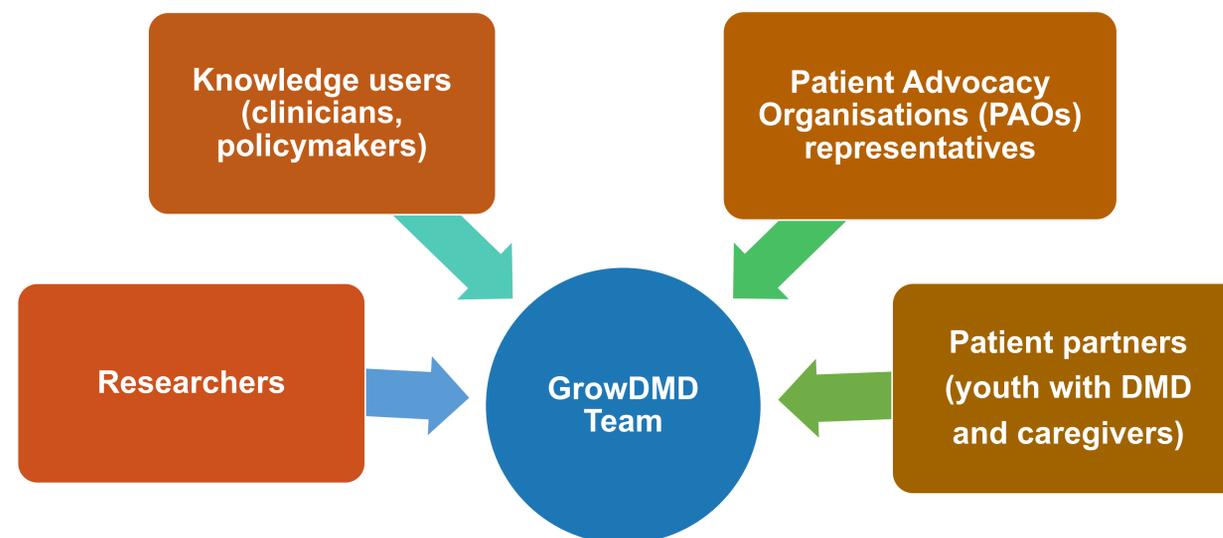
- International Classification of Functioning, Disability and Health (ICF)<sup>2</sup>
- International Classification of Health Interventions (ICHI)<sup>3</sup>

The period of **transition** from pediatric to adult care is particularly challenging for **adolescents with DMD** due to the progression of the condition at a time when youth typically strive for greater independence. In this **international study**, we will analyze the lived experience of DMD patients living in Germany, Italy, and Canada to **develop a conceptual model and policy recommendations** to improve the quality of transition and opportunities for participation for DMD patients which can be applied to other countries.

## PROJECT OVERVIEW



## INTEGRATED KNOWLEDGE TRANSLATION



## RESEARCH PARTNERS



## RESOURCES AND REFERENCES



## SIGNIFICANCE

The integrated nature of this project will allow us to co-create with patients, families, and clinicians a set of general recommendations, tailored to local contexts, that can serve as a model for the transition care path of patients with DMD.

## ACKNOWLEDGEMENTS

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