

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

Comparing patient experiences and systems to optimize care

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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

2022-2023

2023-2024

Scoping review of the literature

Semi-structured interviews with youth, caregivers, and service providers

Surveys with youth and caregivers

Knowledge Translation

2024

2024

INTEGRATED KNOWLEDGE TRANSLATION

Knowledge users (clinicians, policymakers)

Patient Advocacy Organisations (PAOs) representatives

Researchers

GrowDMD Team

Patient partners (youth with DMD and caregivers)

Theoretical Framework and Research questions:

Based on the *International Classification of Functioning, Disability and Health* and the *International Classification of Health Interventions* the aim of the project is to answer the following research questions:

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



Significance:

Despite new pharmacological treatments, care for adolescents with DMD is still a pressing and underdeveloped area. Transition from pediatric to adult care is relevant for thousands of patients with DMD worldwide.

In close collaboration with PAOs and researchers, we strive to ask questions and give answers that really matter. Expected results of GrowDMD include supporting tools for professionals and networking and educational opportunities for patients and families.

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