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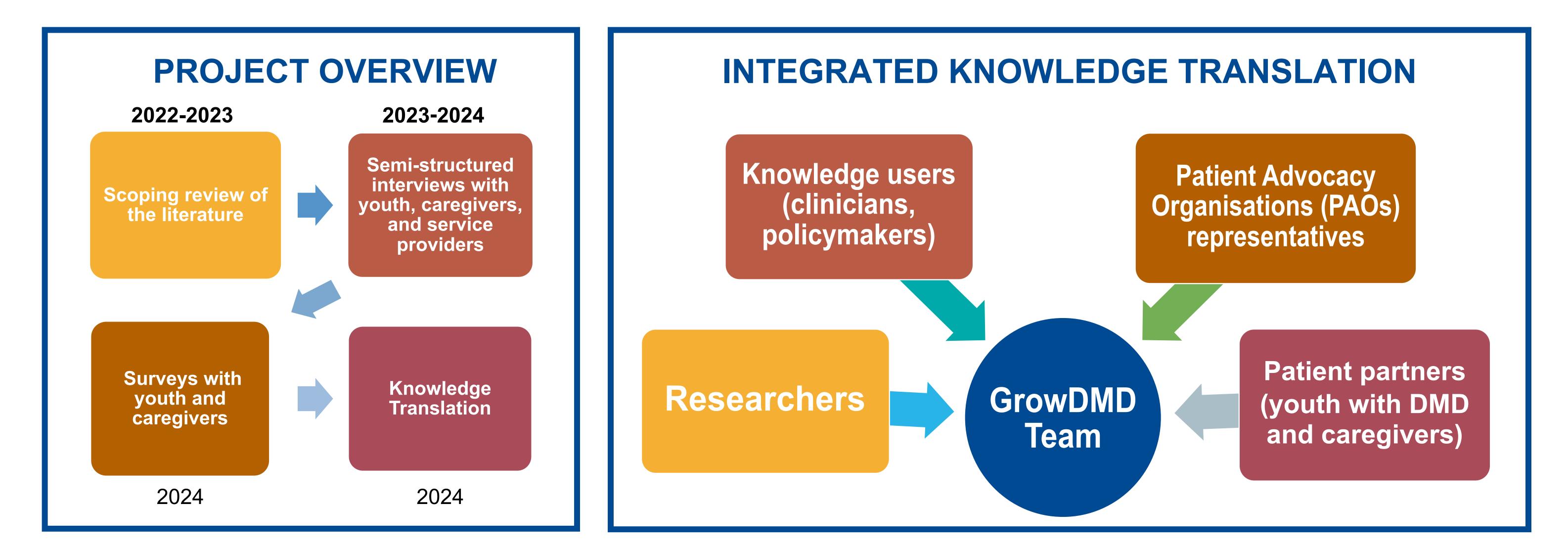
GrowDMD: an International Study on Transition of Youth with Duchenne Muscular Dystrophy (DMD)

Comparing patient experiences and sytems 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.



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 pharmalogical 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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