

# Transition in Duchenne Muscular Dystrophy: Understanding Healthcare Providers’ Roles in an International Context

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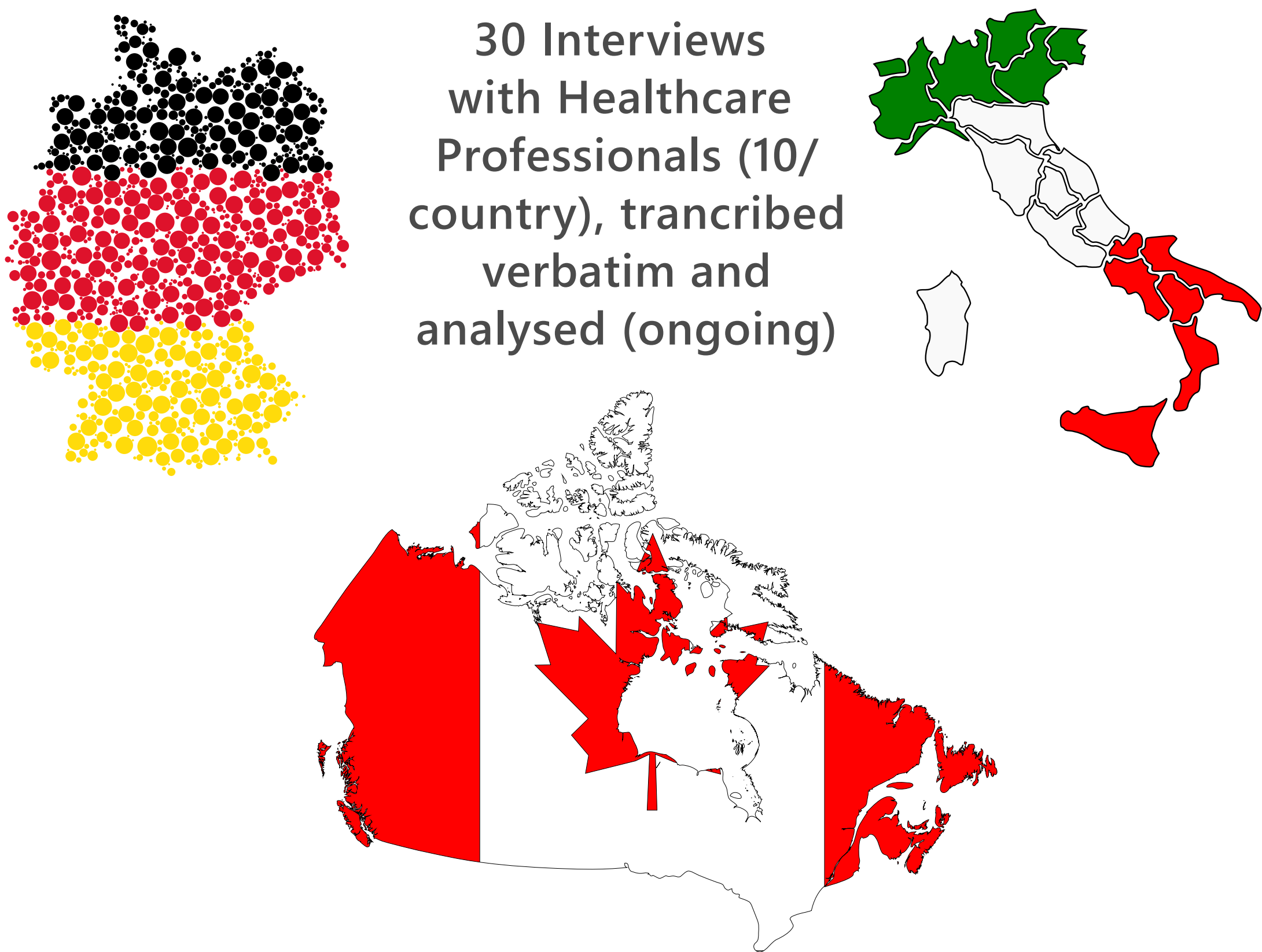
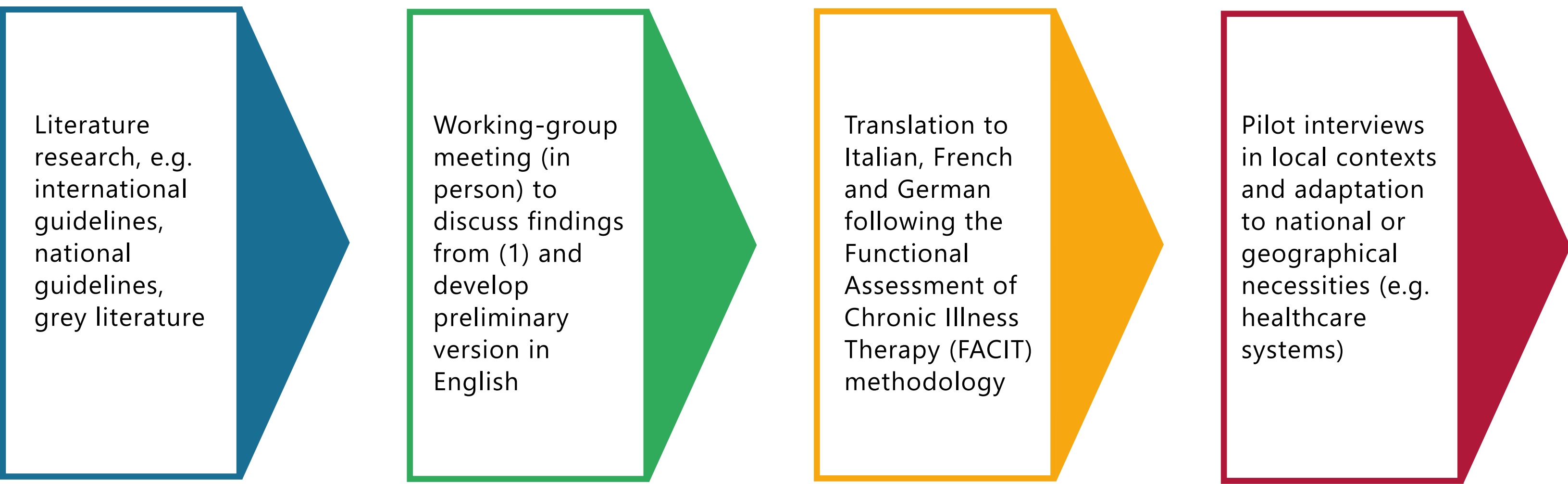
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## Part 1: Background and Research Question

Youth with DMD lose ambulation at 10-15 years. At the same age they strive towards emotional and physical independence, entering adolescence. Transition from pediatric to adult care thus happens at a time of tension between dependence and independence. In the project GrowDMD we aim to **learn about transition by comparing different healthcare systems**. One of our research questions is:

- 1) What measures and strategies are currently implemented in the care organizations of Germany, Italy and Canada to support and facilitate the transition of care?

## Development of a semi-structured interview guide, translation and adaptation



## Interim Results from Qualitative Analysis of Transcripts

Main code	Subcode	Example
Transition	Enablers	"Families really appreciate our starting the conservation early"
	Barriers	"Sometimes we don't know the adult specialists, which makes it difficult"
	Criteria	"I feel that transition usually fits well when they finish school"
	Characteristics/Quality	"We try to do transition bit by bit, with the neuromuscular clinic being last"
	Transition goals	"Ultimately it is about these young adults receiving really good care"
Roles	Organizational/institutional	"We have standardized appointments with the psychosocial team"
	Roles of patients	"And sometimes it is good to just talk to adolescents on their own"
	Roles of caregivers	"Families are different. Some think well in advance, other don't"
	Roles of healthcare providers	"We have known our patients for a long time..."
(Need for) Support	For patients and caregivers	"As a PAO we are connecting patients, trying to build a network"
	For healthcare providers	"It is really helpful to have a standardized protocol"

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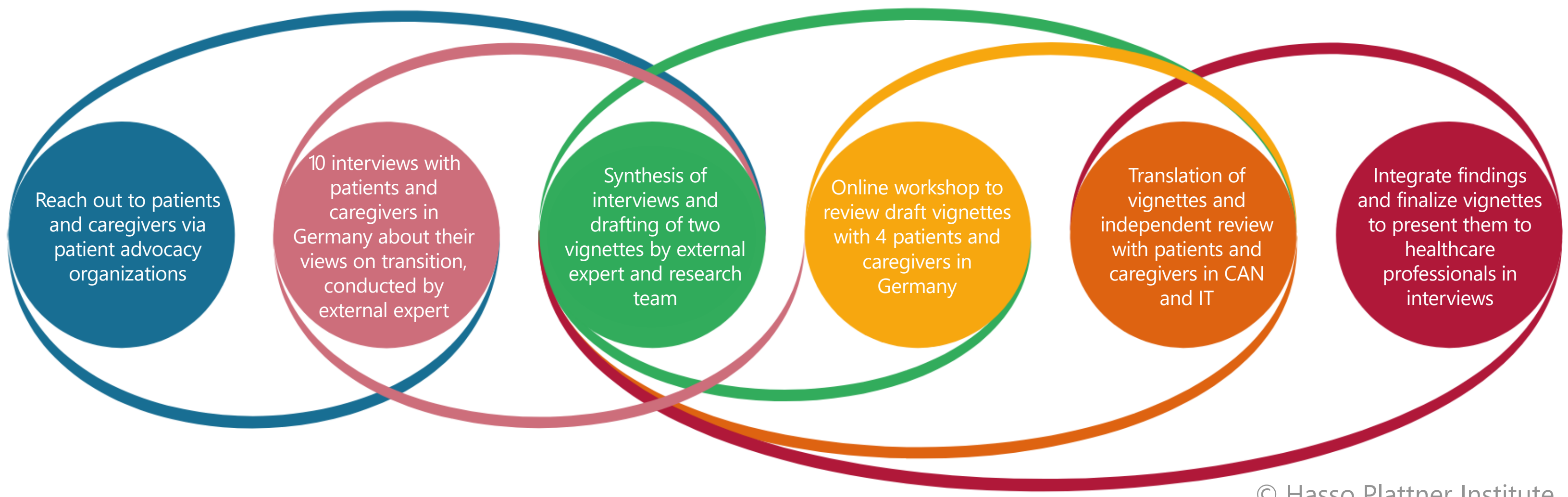
## Part 2: Research Questions and Problem

- 1. How do healthcare professionals respond to the needs expressed by patients and families in DMD?
- 2. How do healthcare professionals’ views about patients’ needs align with the patients’ and caregivers’ perspective?

To answer those questions, we decided to present healthcare providers with case vignettes of two “typical” cases on transition in DMD in a semistructured interview.

**But what is “typical” & who decides on it?**

## Co-Creation of two case vignettes with patients and caregivers across three countries



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**“GrowDMD: Growing into Adulthood with DMD - Comparing Patient Experiences and Systems to Optimize Care”**

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