

Transition from paediatric care to adult care

The young adult and caregiver experience

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Transition from paediatric to adult care services can be a challenging time for families living with Duchenne muscular dystrophy (DMD). As a teenager becomes a young adult, their healthcare needs and personal interests may change. Without proper planning for the future, transition may be a confusing time, and quality of care may be interrupted and affected in the move from a paediatric to an adult care setting.

Research objectives

- **Understand** how transition affects those living with DMD
- **Define** barriers to better transitioning and how to overcome them
- **Empower** young adults to have a more active role in their care

Methodology



In-depth interviews

With 26 families* across UK, Romania and Sweden, about the transition experience



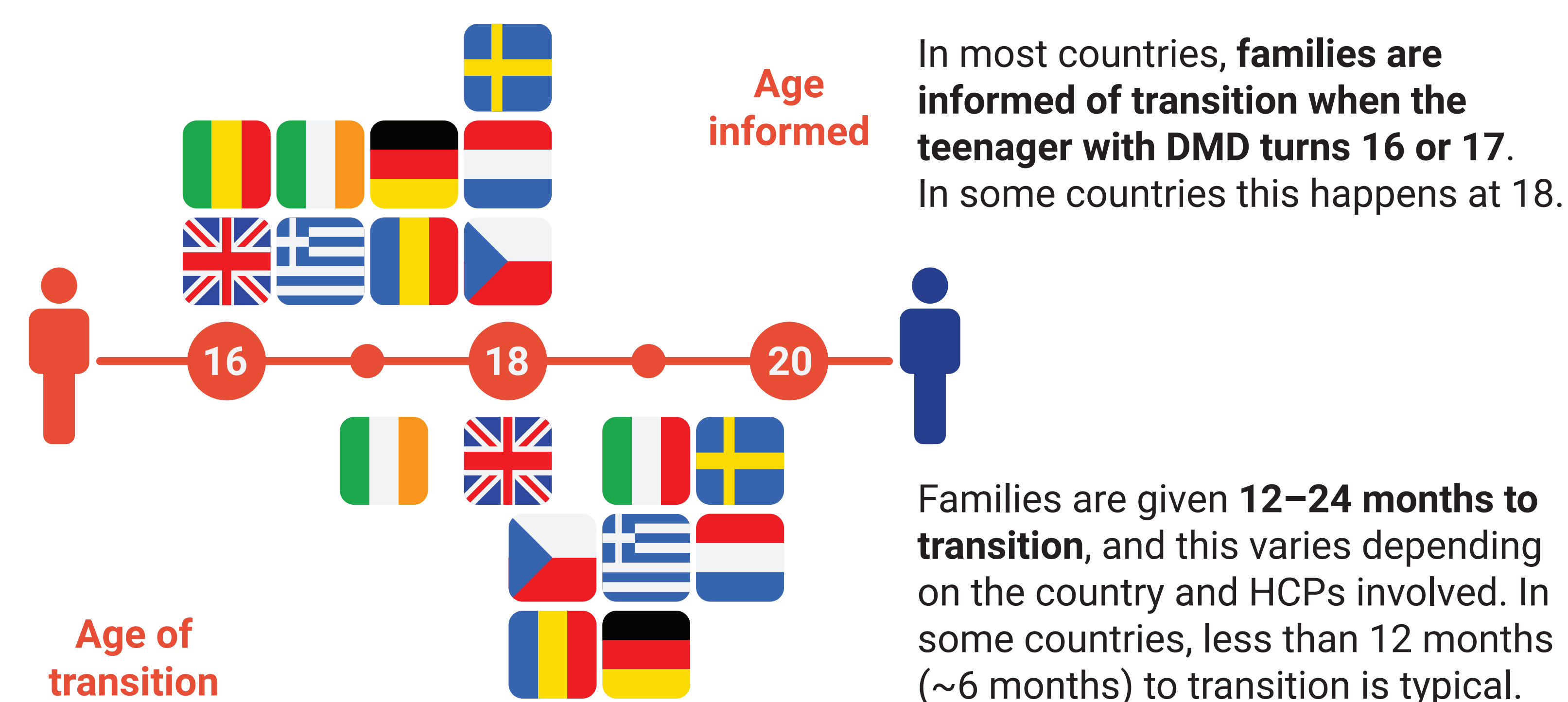
Surveys

Online survey sent to 118 families with DMD across 9 countries**

"I don't quite know where to look, to find the answers... I've got like a Facebook group which is families, but then I find that if you ask a question on there, you probably get 20 different answers" [Parent, UK]

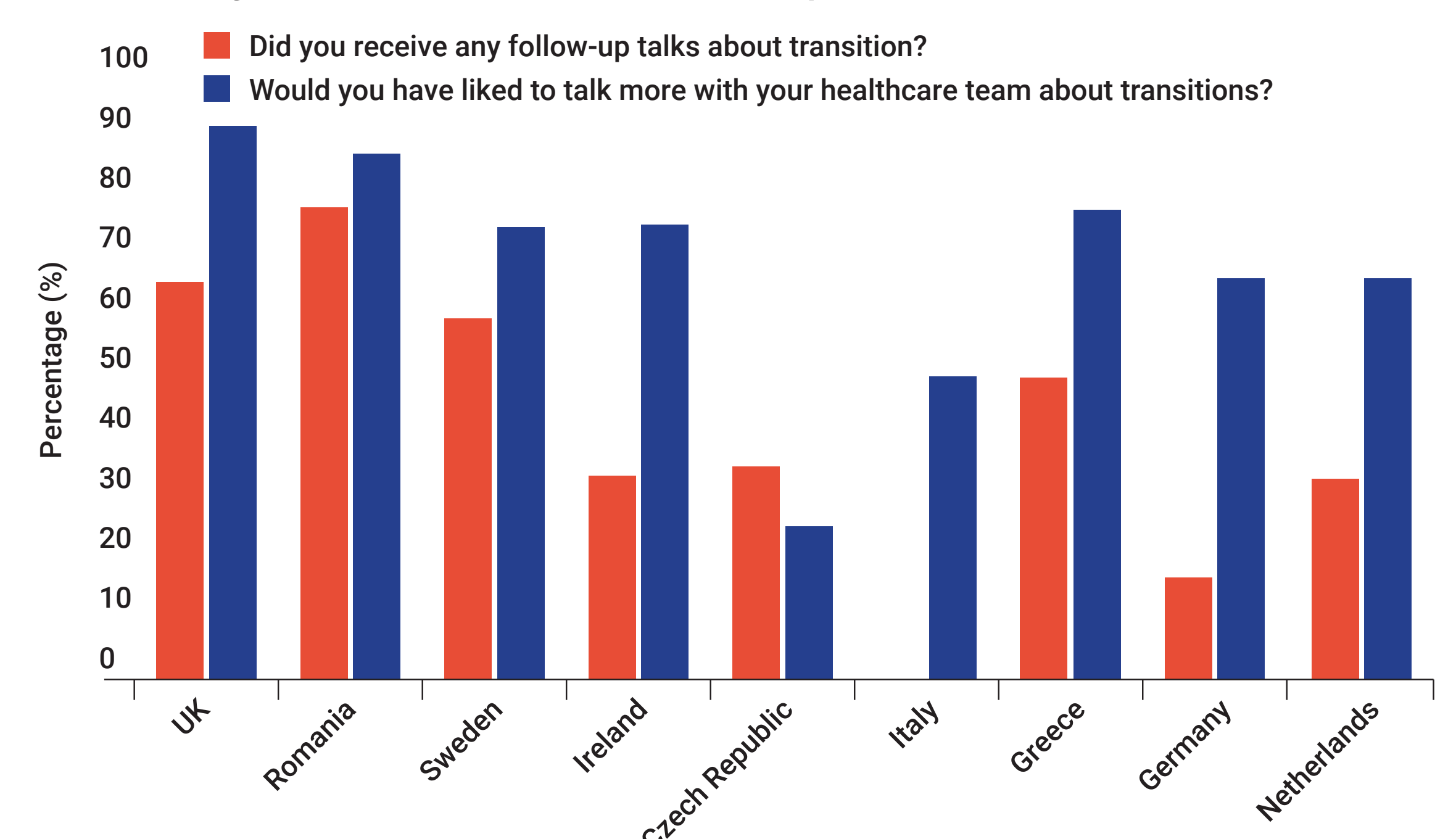
Results

Transition is rushed and unorganised



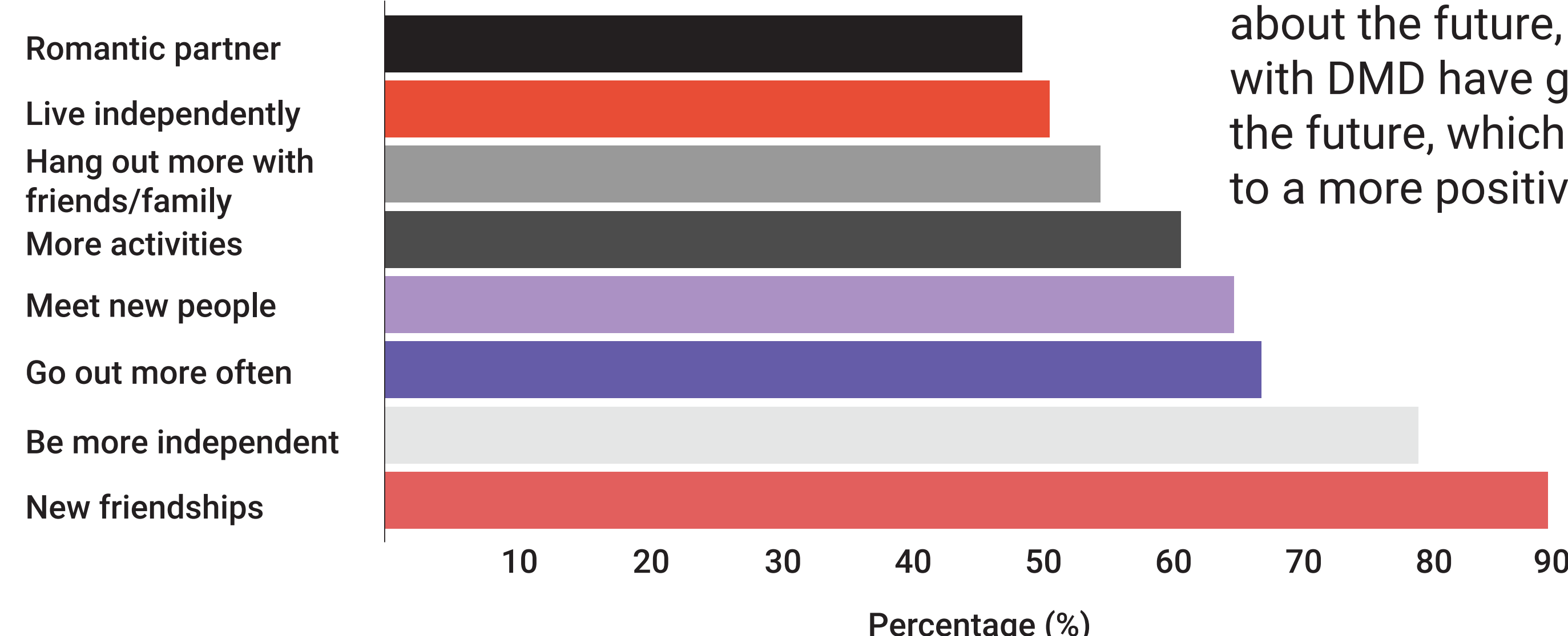
There is a lack of information & resources about transition

Across all countries, families were the main drivers of transition, searching for the information and specialist care needed.



Focusing on goals can improve outlook for young adults

Life and social goals across all countries



Although there is pessimism about the future, those living with DMD have goals about the future, which can help shift to a more positive outlook.

Supporting emotional wellbeing improves confidence

"It is the same with the psychologist we do therapy with. If we feel the need to cry, we cry. If we feel the need to scream, we scream. We are not hiding these [emotions] anymore." [Parent, Romania]

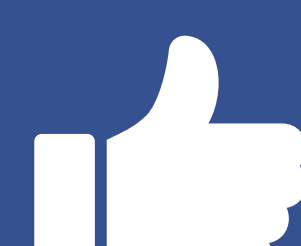
Participants who received counselling or other mental health support expressed more self-confidence and independence.

"It was last year. Once you turn 18 it happens immediately, it's very quick. You might not be prepared for it but once you turn 18 it happens." [Parent, Sweden]

Opportunities to improve the transition experience



Tailored education outlining the transition pathway and what to expect.



Encouragement to start future planning and to seek mental health support when needed.



Motivate young adults living with DMD to become more involved with conversations and decisions around their health.

* 13 pre-transition and 13 post-transition young adults and parents.

** Czech Republic, Germany, Greece, Ireland, Italy, the Netherlands, Romania, Sweden, UK.

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