



8th ERN EURO-NMD Annual Meeting

ERN EURO-NMD Survey on Transition from childhood to adulthood in NMDs

5th – 7th March 2025

Teresinha Evangelista
APHP

ERN EURO-NMD Transition task force

Kristl Claeys

Thomas Sejersen

Ulrike Schara-Schmidt

Susana Quijano-Roy

Isabella Moroni

Charlotte Handberg

Ros Quinlivan

Teresinha Evangelista

Houda Ali

BACKGROUND

WP 9 - Establishment of general guidance for the transition from child to adulthood

Establishment of the TASK FORCE

Action : Elaborate General recommendations for NMD

Survey

- **Anonymous, sent to HCPs in 26 countries:**

- All ERN EURO-NMD HCPs

- UK neuromuscular centres

- **Target population:** clinicians, other healthcare professionals

- **Response period:** 26th September to 21st October 2024

- Multiple answers from the same HCP were allowed

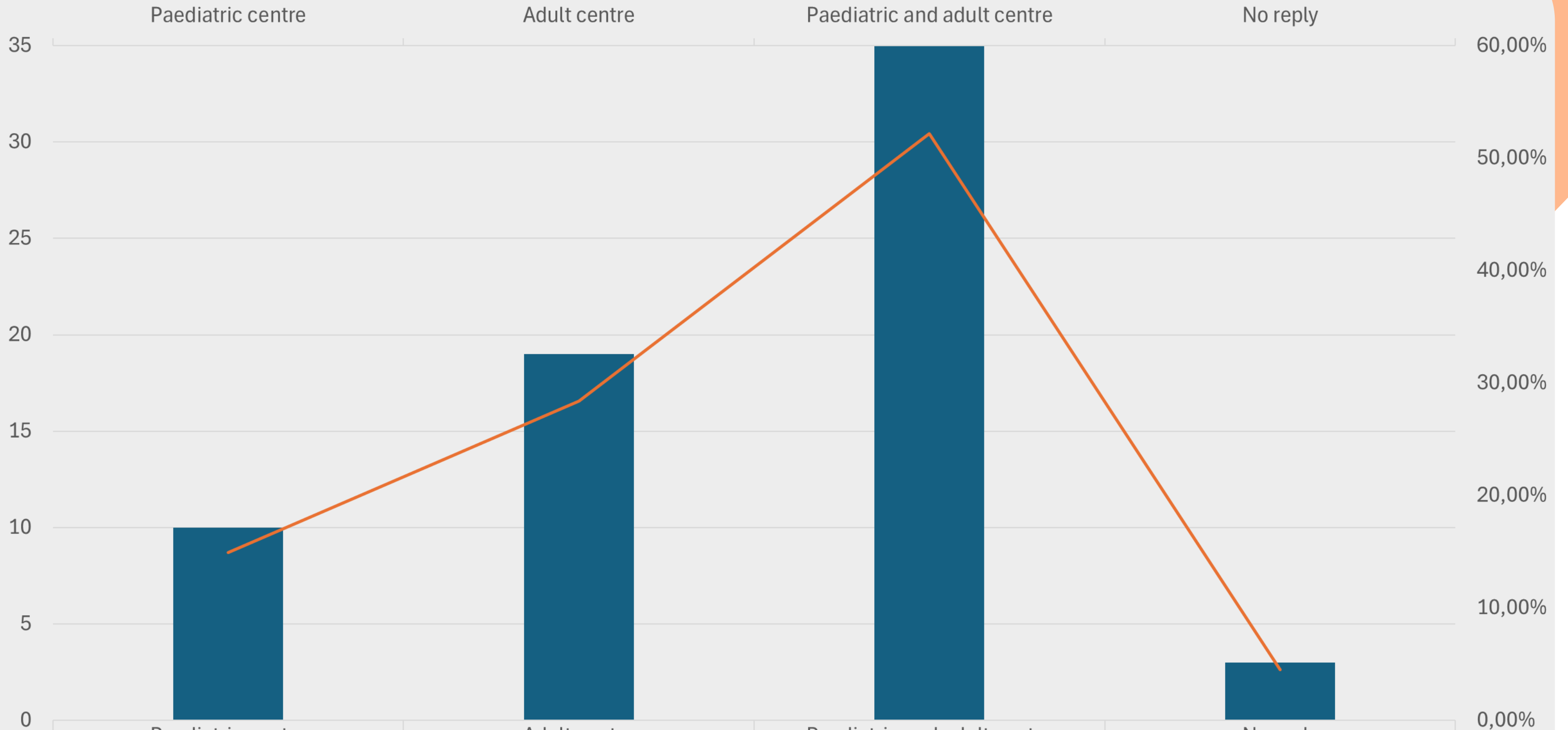
Responses:

- 20 countries

- 67 responses in total

- Countries not represented: Bulgaria; Ireland; Luxembourg; Norway, Poland; Slovenia

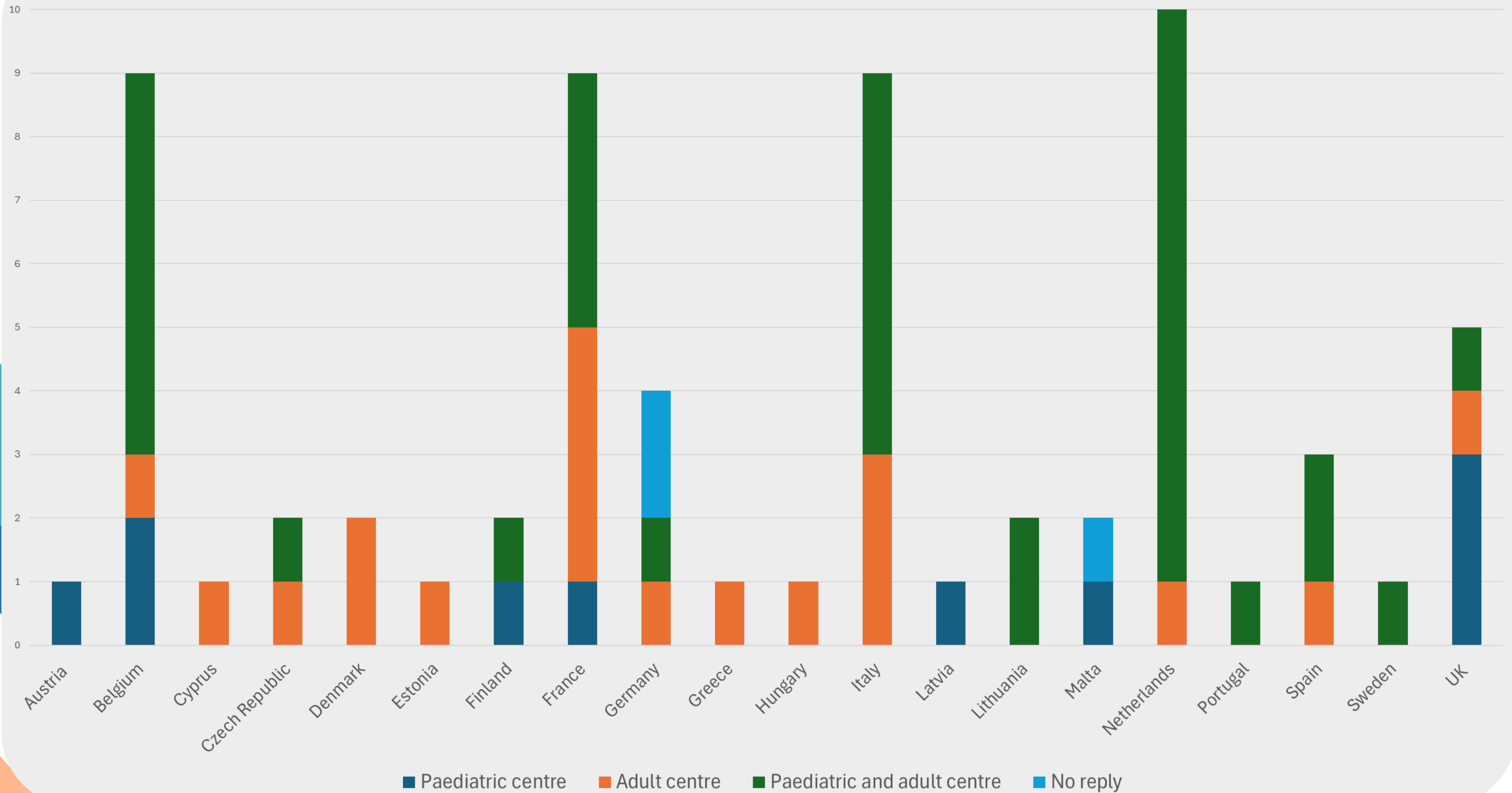
TYPE OF CENTRE



■ Série1
— Série2

— Série3
■ Série4

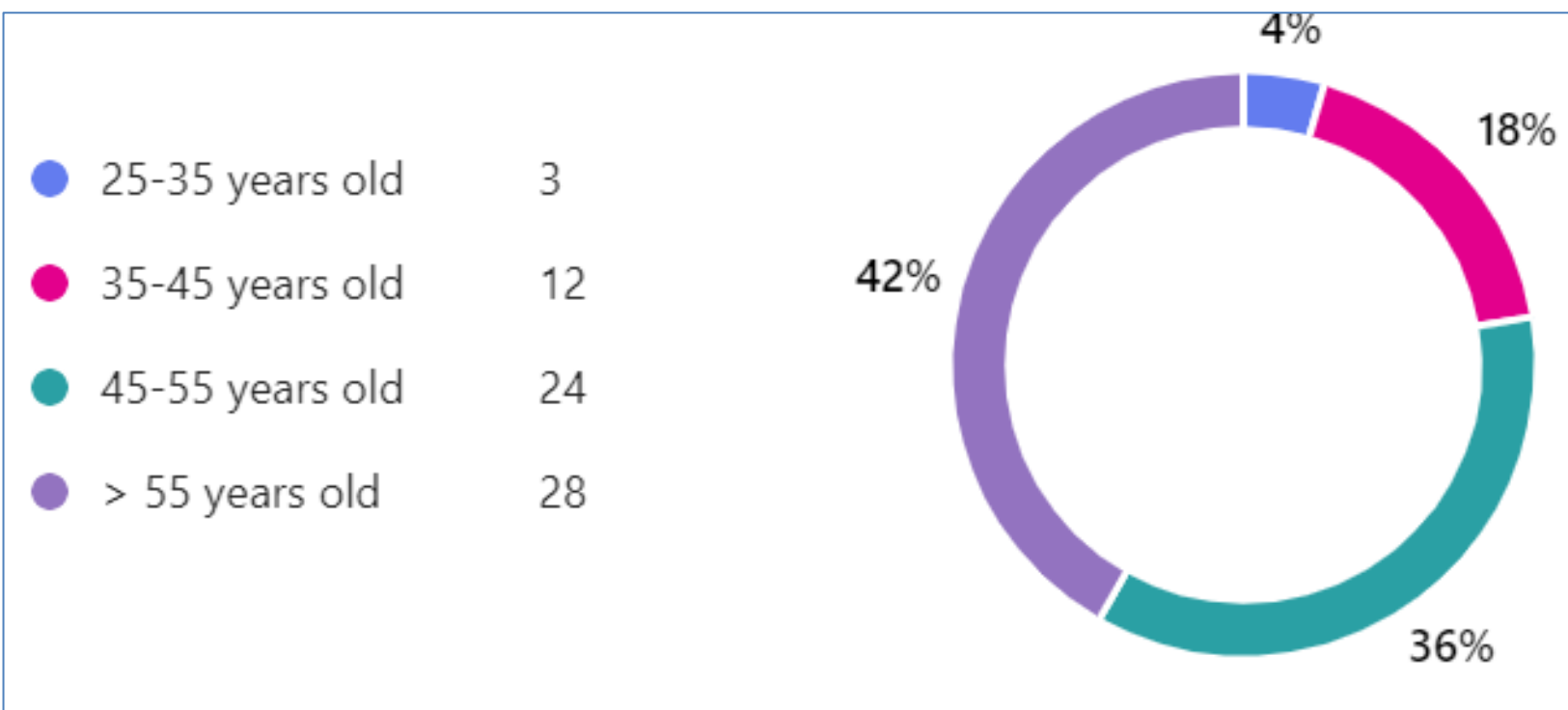
NUMBER OF ANSWERS AND TYPE OF CENTRE PER COUNTRY



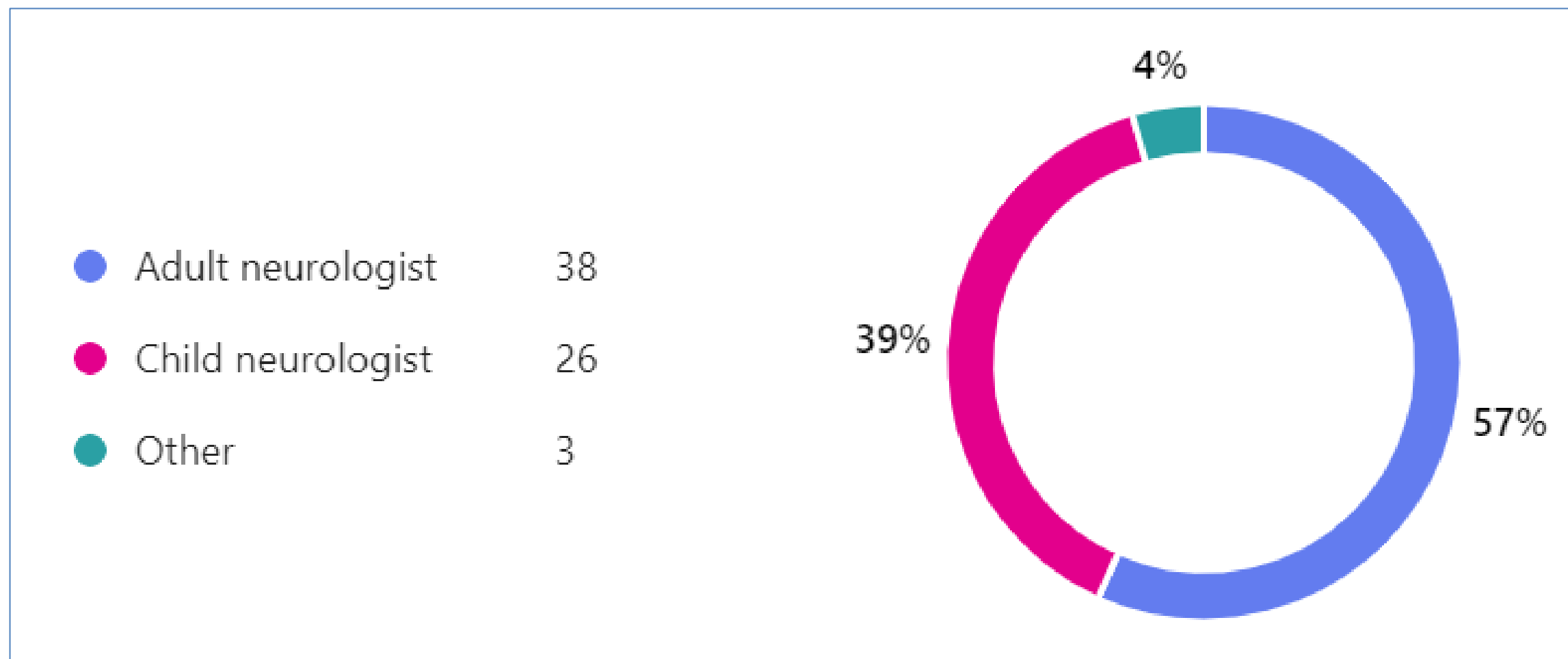
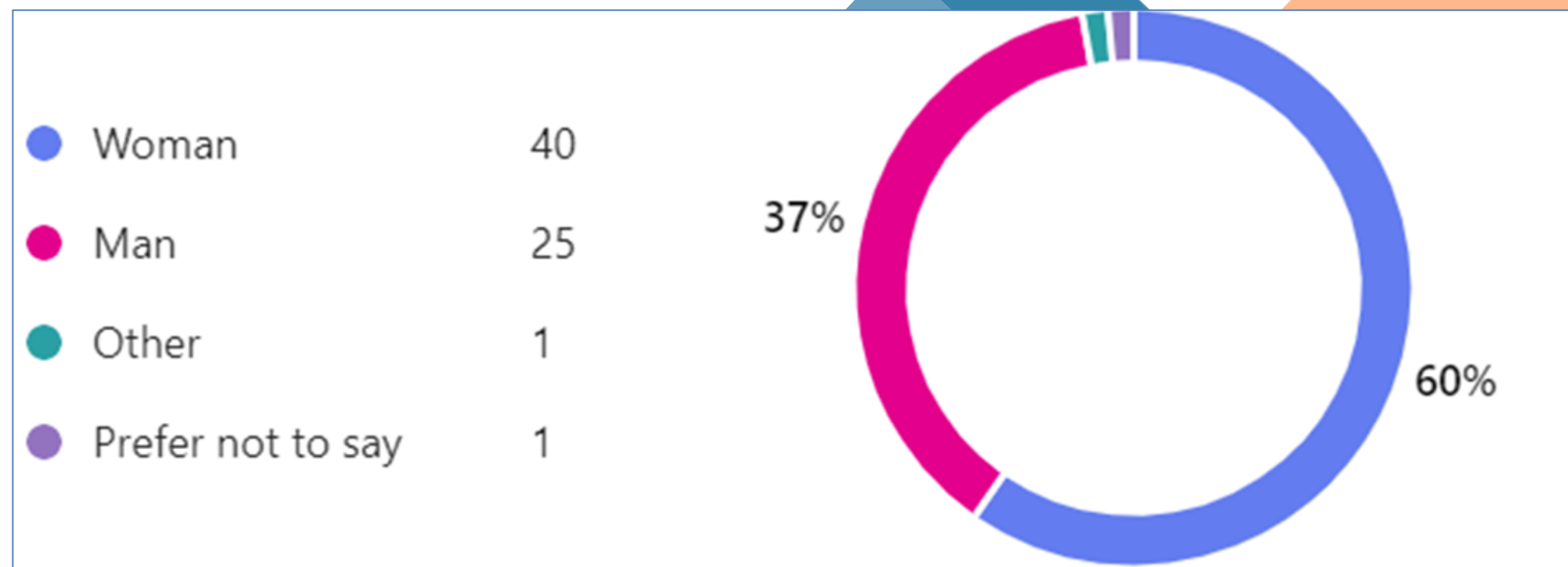
■ Paediatric centre
 ■ Adult centre
 ■ Paediatric and adult centre
 ■ No reply

■ Paediatric centre
 ■ Adult centre
 ■ Paediatric and adult centre
 ■ No reply

AGE RANGE



GENDER

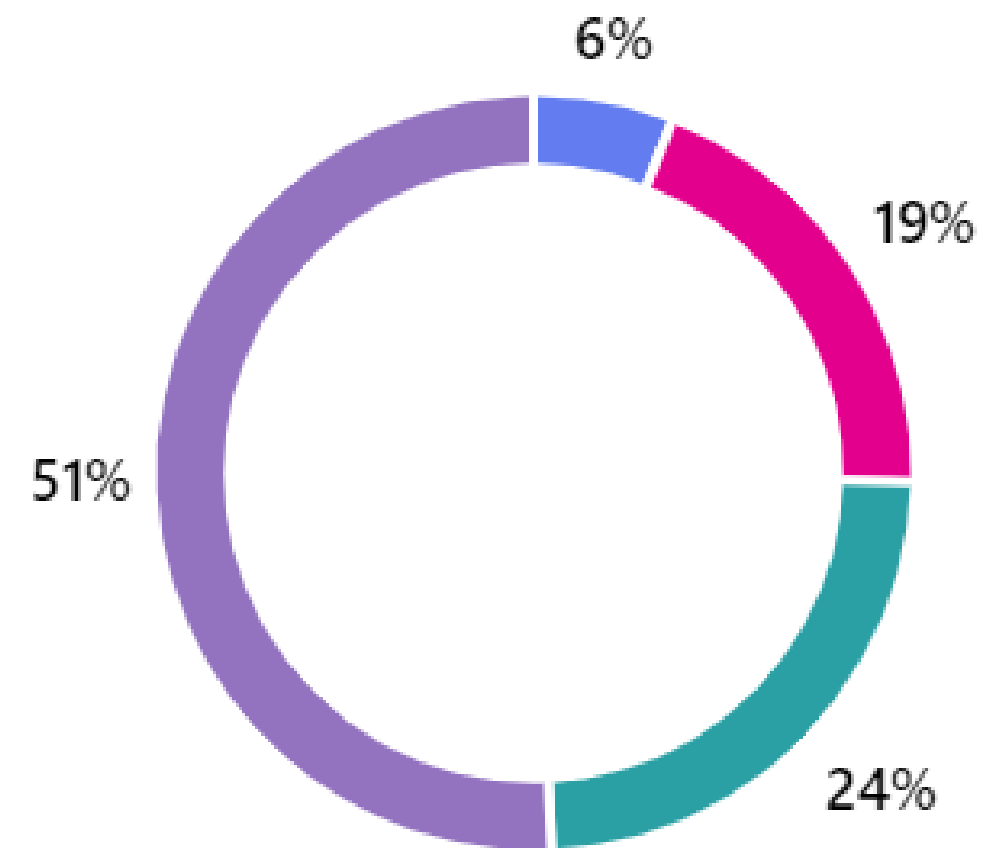


Area of expertise

- Care coordinator, Post-doc researcher
- Rehabilitation physician
- Clinical neurophysiology

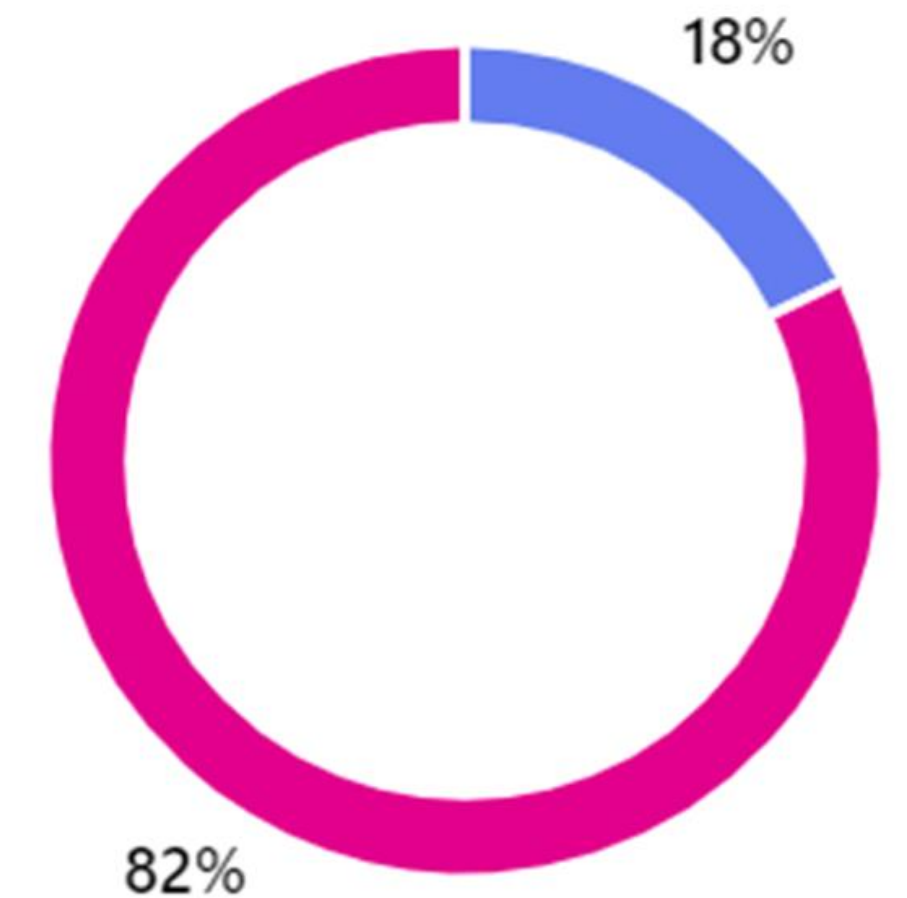
Years of experience working with NMD patients

● < 5 years	4
● 5-10 years	13
● 10-20 years	16
● > 20 years	34



Have you received any specific training on transitioning patients, especially those with NMDs, from pediatric to adult care?

● Yes	12
● No	55



What are the common barriers or challenges faced in transitioning patients with NMDs from pediatric to adult care?

	ALL COUNTRIES
Need for a multidisciplinary team	1,9
Scarce education/training in transition	1,7
Lack of financial support for transition programs	1,6
Lack of adequate clinical settings for young adults with special needs*	1,3
Parents/caregivers preference to remain in paediatric clinic	0,8
Emotional attachment of paediatric care providers to their patients	0,6
Difficulty in obtaining timely appointments in the adult system	0,3
Lack of communication between adult and paediatric teams	0,1
Limited adult providers willing or able to accept the patients	-0,3
Difficulty in obtaining paediatric medical records	-2,2

	Austria	Belgium	Cyprus	Czech Republic	Denmark	Estonia	Finland	France	Germany	Greece	Hungary	Italy	Latvia	Lithuania	Malta	Netherlands	Portugal	Spain	Sweden	UK
	4,0	-0,7	4,0	-1,0	1,0	4,0	1,0	2,7	3,5	4,0	4,0	3,3	2,0	2,0	2,0	0,6	4,0	2,0	0,0	3,2
	4,0	2,4	4,0	0,0	3,0	4,0	2,0	0,0	2,0	4,0	0,0	2,4	2,0	4,0	2,0	0,4	2,0	0,7	4,0	2,4
	4,0	1,1	4,0	4,0	3,0	2,0	-2,0	1,3	3,5	4,0	0,0	3,1	2,0	4,0	-1,0	0,0	2,0	-0,7	2,0	2,0
	4,0	1,1	4,0	-1,0	0,0	2,0	2,0	0,7	2,0	2,0	0,0	2,2	2,0	3,0	2,0	-0,2	2,0	2,0	4,0	1,6
	2,0	2,7	-2,0	-1,0	-3,0	2,0	-2,0	1,6	0,5	2,0	2,0	1,6	0,0	1,0	0,0	-0,4	0,0	0,7	-2,0	2,0
	0,0	1,3	0,0	-1,0	-2,0	2,0	-1,0	2,0	0,5	2,0	0,0	0,2	2,0	3,0	0,0	-1,0	2,0	2,7	-4,0	1,6
	0,0	-0,2	0,0	-1,0	-1,0	4,0	3,0	0,0	1,0	0,0	4,0	0,4	2,0	1,0	3,0	-2,2	2,0	0,0	2,0	2,4
	4,0	-0,4	2,0	-2,0	-1,0	2,0	-1,0	0,7	0,5	0,0	2,0	0,0	2,0	-1,0	0,0	-1,6	2,0	1,3	2,0	1,2
	2,0	-2,0	2,0	-1,0	-3,0	2,0	-2,0	0,0	1,0	0,0	2,0	-0,4	2,0	2,0	-2,0	-1,4	-2,0	-0,7	4,0	2,8
	0,0	-2,4	-2,0	-3,0	-3,0	-4,0	-3,0	-3,3	-0,5	0,0	4,0	-1,8	-2,0	-3,0	-2,0	-3,4	-2,0	-0,7	-4,0	-0,4

Global average score	0,6
Total responses	67

2,4	0,3	1,6	-0,7	-0,6	2,0	-0,3	0,6	1,4	1,8	1,8	1,1	1,4	1,6	0,4	-0,9	1,2	0,7	0,8	1,9
1	9	1	2	2	1	2	9	4	1	1	9	1	2	2	10	1	3	1	5

Color	Item
Red	Strongly agree
Orange	Agree
Grey	Neutral
Light Blue	Disagree
Dark Blue	Strongly disagree

In your opinion, which of the following are needed for improving the transition process? Please rate from 1 (minor need) to 5 (maximum need):

	ALL COUNTRIES	Austria	Belgium	Cyprus	Czech Republic	Denmark	Estonia	Finland	France	Germany	Greece	Hungary	Italy	Latvia	Lithuania	Malta	Netherlands	Portugal	Spain	Sweden	UK
A transition Protocol	3,9	5,0	4,0	5,0	4,0	3,0	5,0	4,5	3,2	3,8	5,0	5,0	4,4	5,0	5,0	3,5	3,4	5,0	2,3	4,0	4,4
Including the patient's views and preferences to the planning of transition	3,8	5,0	4,0	5,0	3,0	2,5	3,0	4,0	3,2	3,8	4,0	4,0	4,3	5,0	5,0	3,5	3,3	4,0	3,0	5,0	4,8
A dedicated coordinator responsible for transition	3,7	5,0	3,9	3,0	4,0	3,0	5,0	3,0	2,8	4,0	5,0	2,0	4,4	5,0	5,0	4,5	3,0	4,0	3,0	4,0	4,8
Implementation of national recommendation about adolescent's transition to adult care system	3,6	3,0	3,4	5,0	4,0	2,5	4,0	4,0	3,1	4,0	5,0	5,0	4,1	5,0	5,0	4,0	3,0	5,0	2,7	3,0	4,0
Joint consultations between adult and paediatric teams	3,6	5,0	3,9	5,0	3,0	2,0	3,0	3,0	3,4	4,0	5,0	5,0	4,1	3,0	5,0	3,0	2,7	5,0	2,0	5,0	4,6
Obtaining financial support	3,5	5,0	3,6	3,0	5,0	2,0	4,0	1,5	2,8	4,8	5,0	1,0	4,7	5,0	5,0	1,5	2,5	3,0	3,0	5,0	4,8
Introducing transition courses in the training programs for child and adult neurologists	3,5	5,0	3,4	5,0	3,5	3,0	4,0	3,5	2,6	3,8	4,0	4,0	4,3	5,0	5,0	3,5	2,6	5,0	2,7	4,0	4,0
Establishment of a network of specialized care, including physicians, who care for adolescent and young adults with NMDs	3,4	4,0	2,9	5,0	3,0	2,5	4,0	2,5	2,6	4,0	5,0	5,0	4,7	5,0	5,0	3,5	2,8	5,0	2,7	4,0	3,6
Global average score	3,5	4,7	3,3	4,3	3,8	2,5	4,0	2,5	2,6	4,2	4,7	3,3	4,6	5,0	5,0	2,8	2,6	4,3	2,8	4,3	4,1
Total responses	67	1	9	1	2	2	1	2	9	4	1	1	9	1	2	2	10	1	3	1	5

Col or	Item	Min	Max
Red	Maximum need	4,01	5
Orange	High need	3,01	4
Light Blue	Moderate need	2,01	3
Dark Blue	Minor need	1	2

Strengths and Best Practices

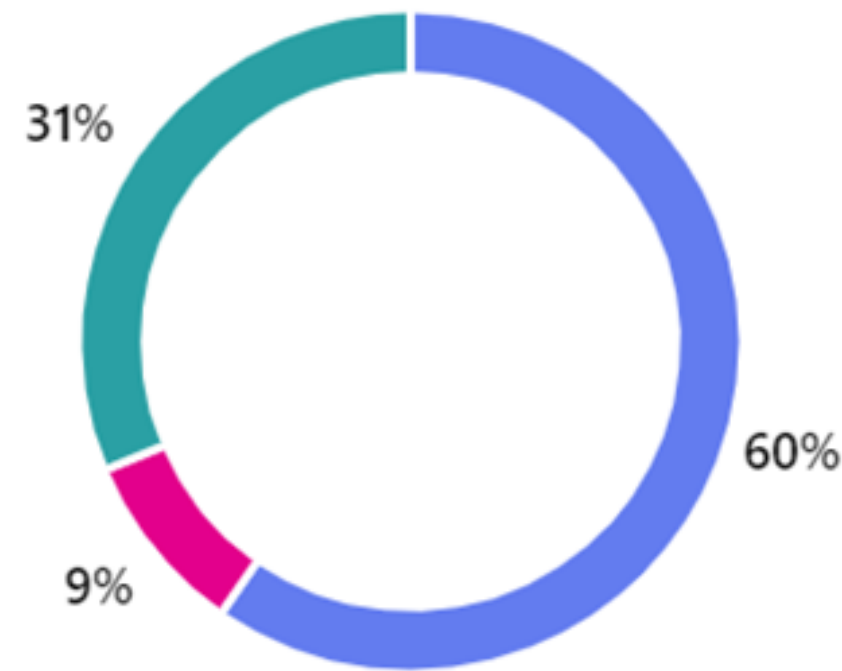
- ✓ In many centers pediatric/adult teams are part of the same center
- ✓ For most centres there is a transition process not just transfer
- ✓ There is an equal involvement in the lead of the process (paediatric and adult clinicians)
- ✓ Other allied professionals are starting to be involved in the coordination process
- ✓ In many centers there are shared information systems
- ✓ Multidisciplinary Meetings: Annual or monthly discussions
- ✓ Some centers have dedicated transition teams
- ✓ More rarely there are dedicated Transition Clinics

Where Are the Gaps?

- ✘ Lack of training at all levels
- ✘ Lack of structured protocols/guidelines. High variability across hospitals/countries
- ✘ Lack of dedicated funding and staff
- ✘ Adult neurologists may face difficulties in following pediatric diseases due to different training approaches
- ✘ Most centres do not use any tool to assess readiness for transition
- ✘ Most centers do not collect feedback from patients/parents

Do you think that the European networks, and in particular EURO-NMD can facilitate the optimization of transition care for patients with NMDs in Europe?

● Yes	40
● No	6
● I do not know	21

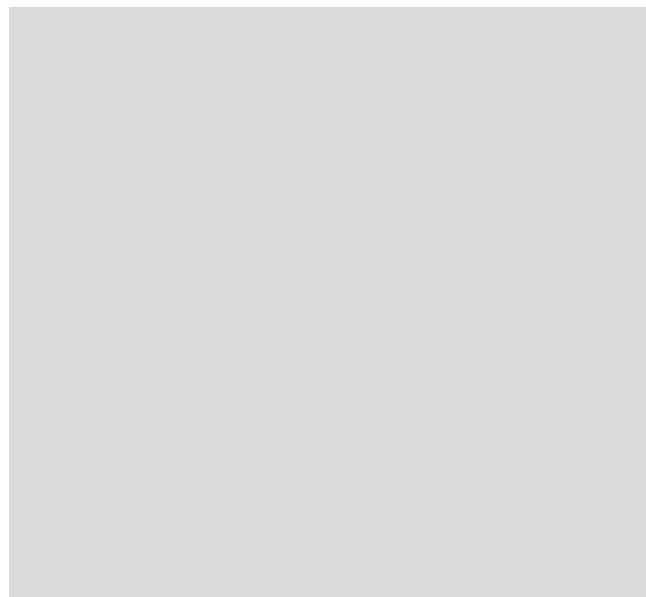


SUGGESTIONS:

- **Develop and distribute standardized transition guidelines** that are flexible and adaptable to local needs.
- **Organize structured training programs** (webinars, workshops, summer schools) to educate both clinicians and patients.
- **Advocate for political and financial support** to ensure sustainable transition programs across Europe.
- Facilitate cross-border collaboration and best practice sharing through **an interactive platform**.

Key Takeaways

- ✓ Transition is essential for neuromuscular patients but remains inconsistent.
- ✓ Training gaps and organizational differences create challenges
- ✓ Collaboration and structured protocols can significantly improve transition outcomes
- ✓ Standardized training, follow-up systems, and patient-centered approaches are needed



Time for Questions

- The ERN EURO-NMD is funded by the European Commission under the EU4Health programme (EURO-NMD 23-27 — 101156434 — EU4H-2023-ERN2-IBA)