

Evgeniya Vedernikova¹, Nicole Gusset¹, Yasemin Erbas¹

¹SMA Europe, Germany

Spinal Muscular Atrophy (SMA) is a rare genetic and progressive neuromuscular condition occurring in approximately 1 in 6,000 to 10,000 live births.

What is EUPESMA?

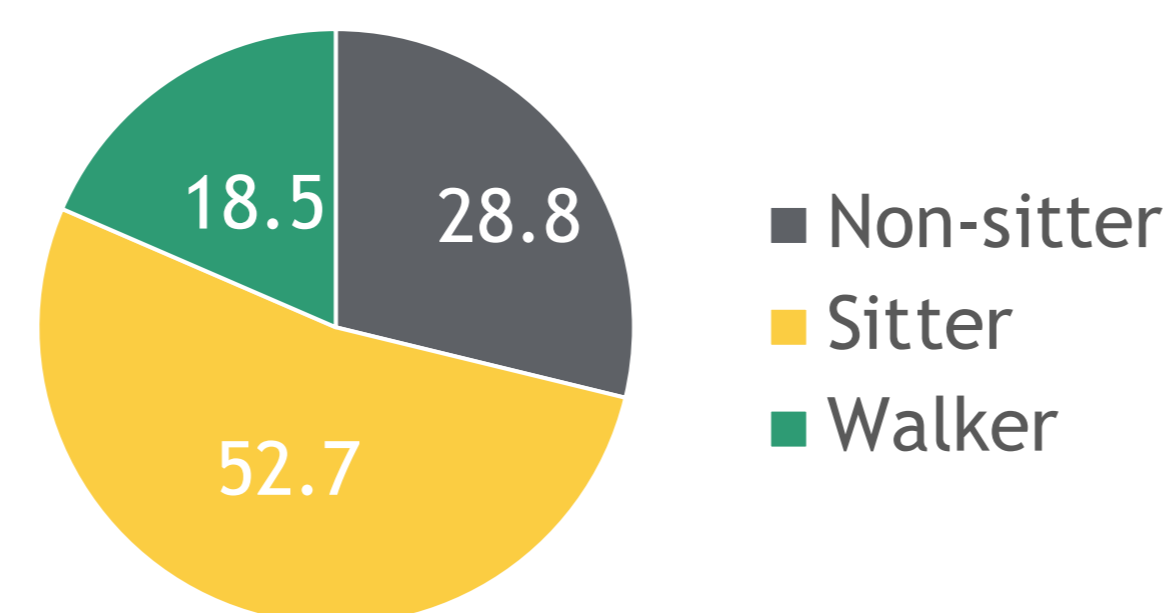
- SMA Europe's **European Patient Expectation Survey (EUPESMA)** Series are designed to *map* the experiences and to *ascertain* the needs and wants of people living with SMA, to *help* SMA Europe advocate for equal access to optimal treatment and care in Europe.
- EUPESMA 2021:** focus on physiotherapy, nutrition, and treatment experiences.

Who participated?

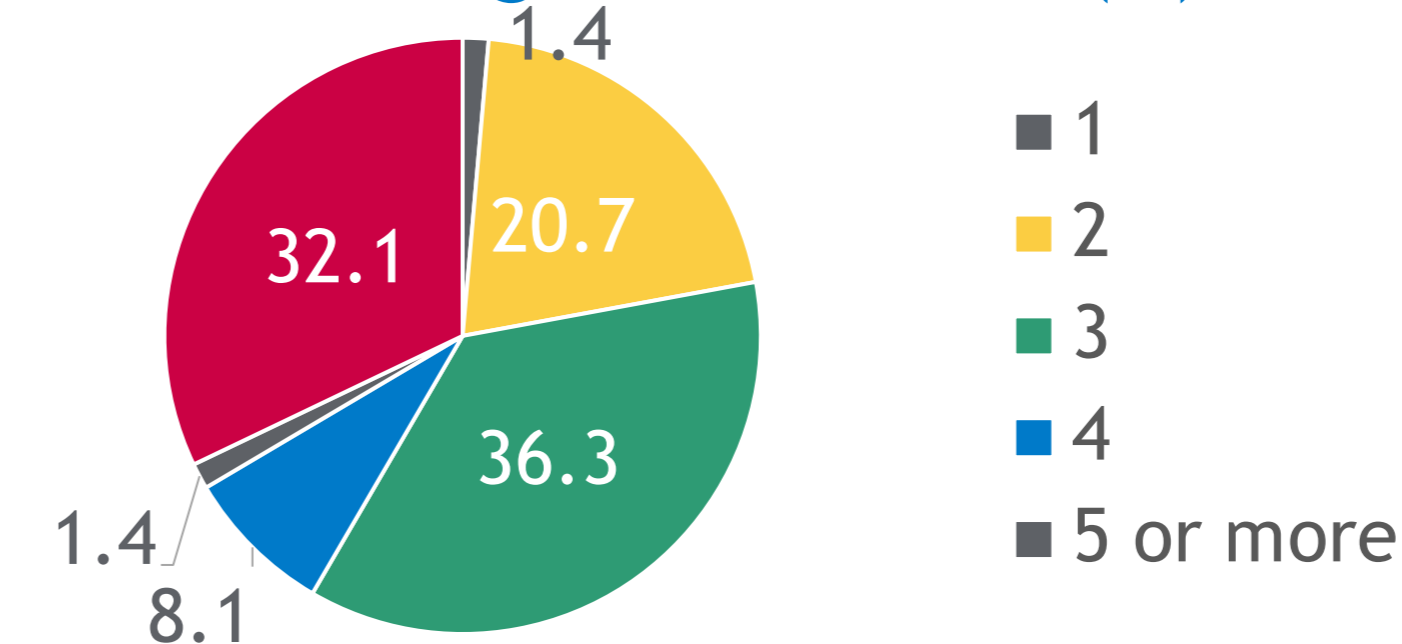
- 1,808** individuals from **57** countries & territories in **20** languages
- With mean age of 24.86; for gender: 50.3% of males and 48.5% of females



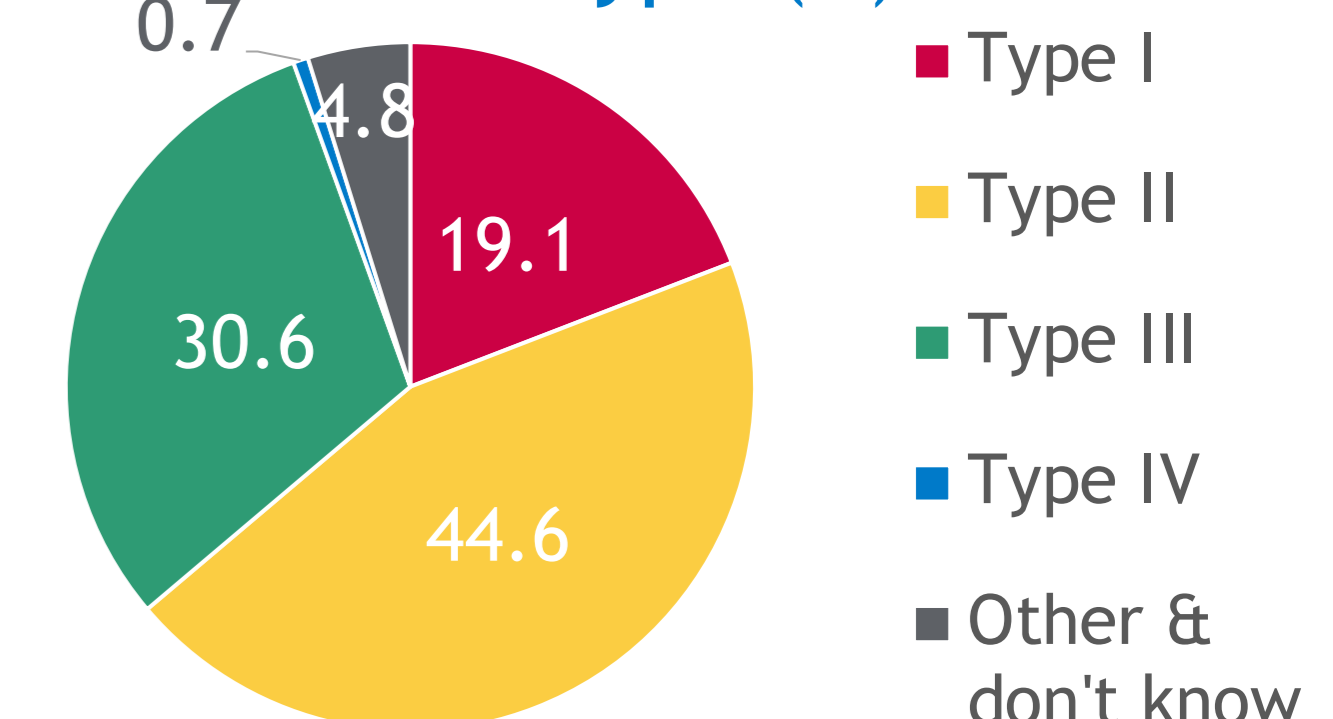
Mobility status (%)



SMN2 gene number (%)



SMA type (%)

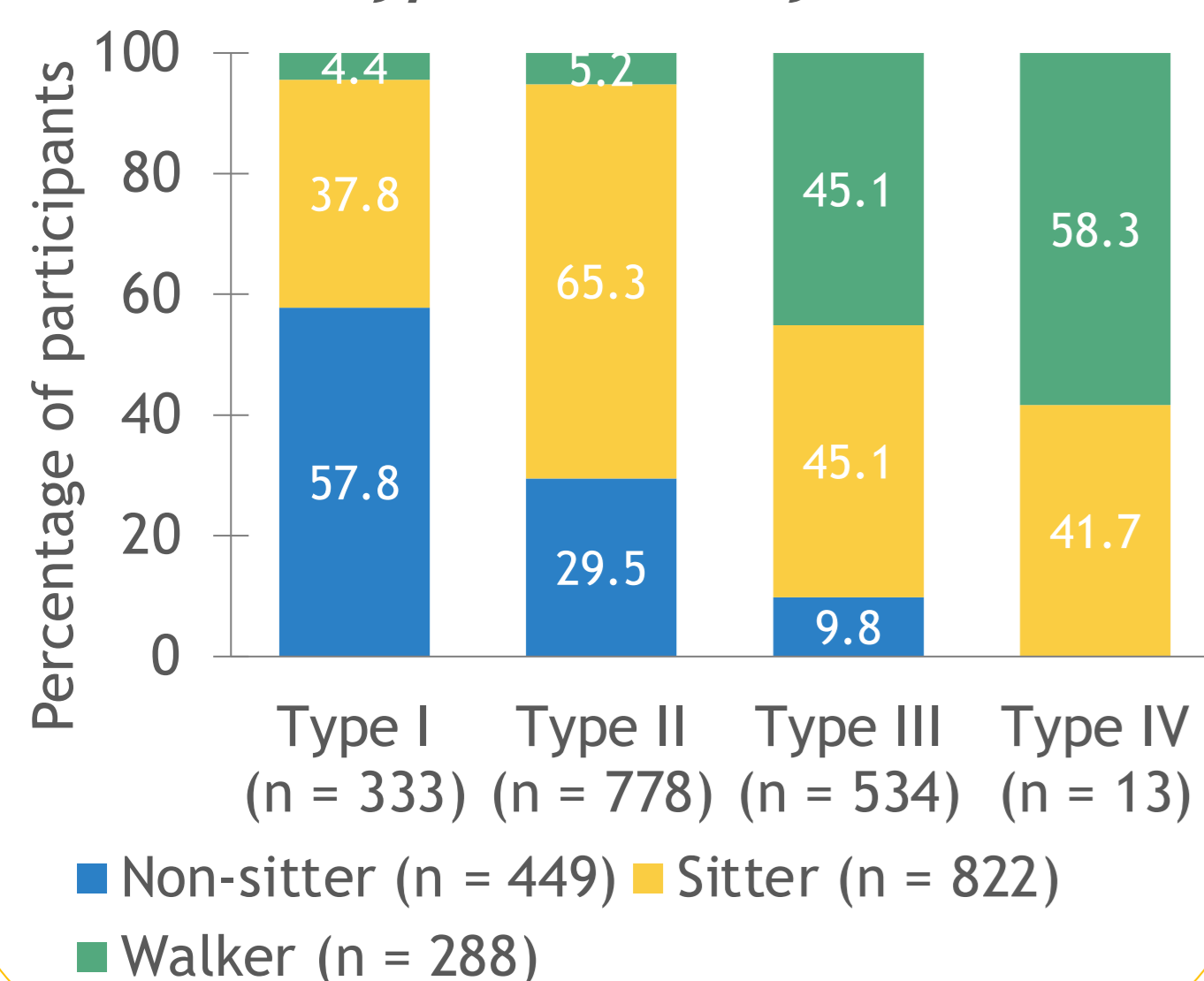


What did we find?

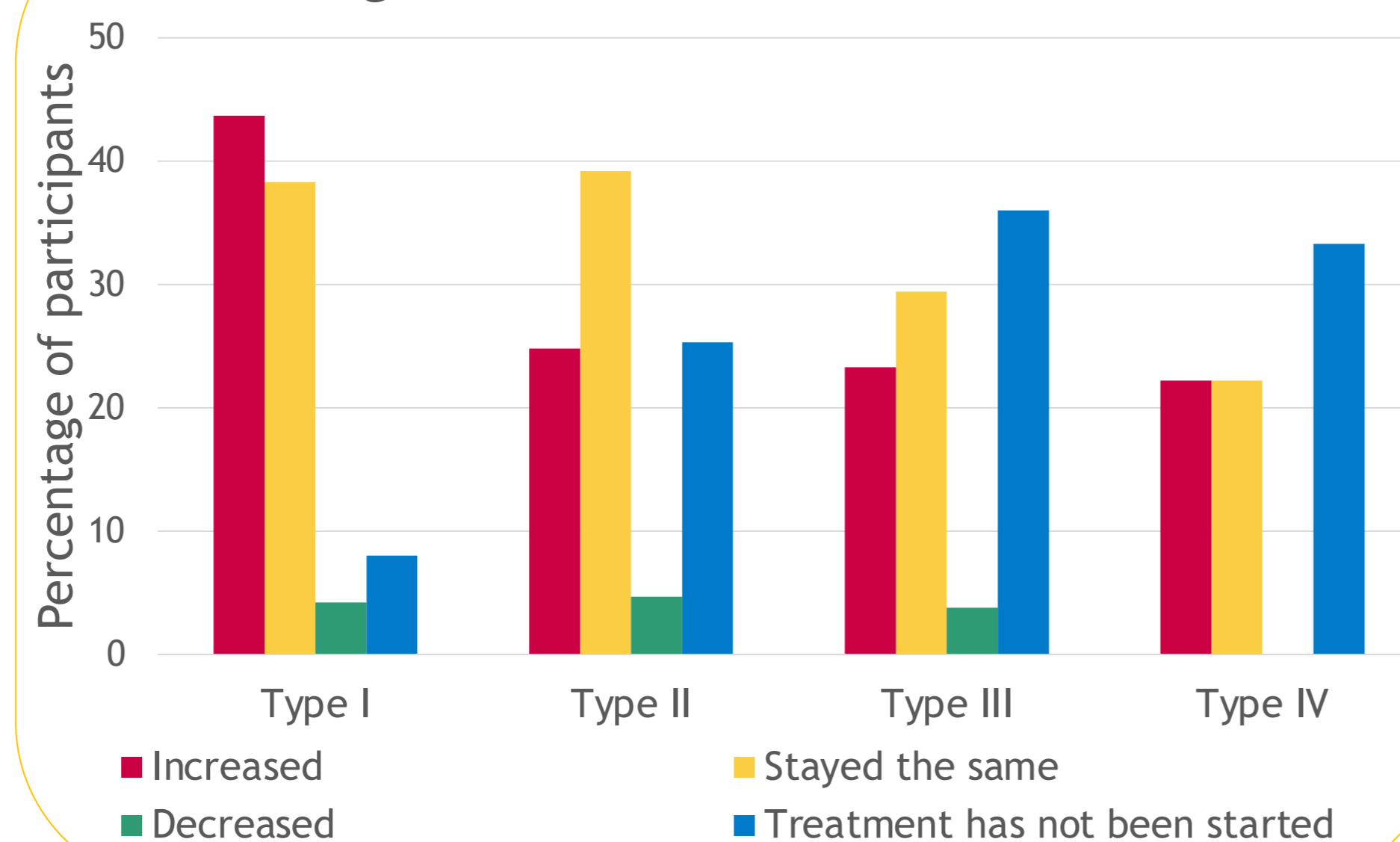
Physiotherapy (PT)



SMA type & mobility status

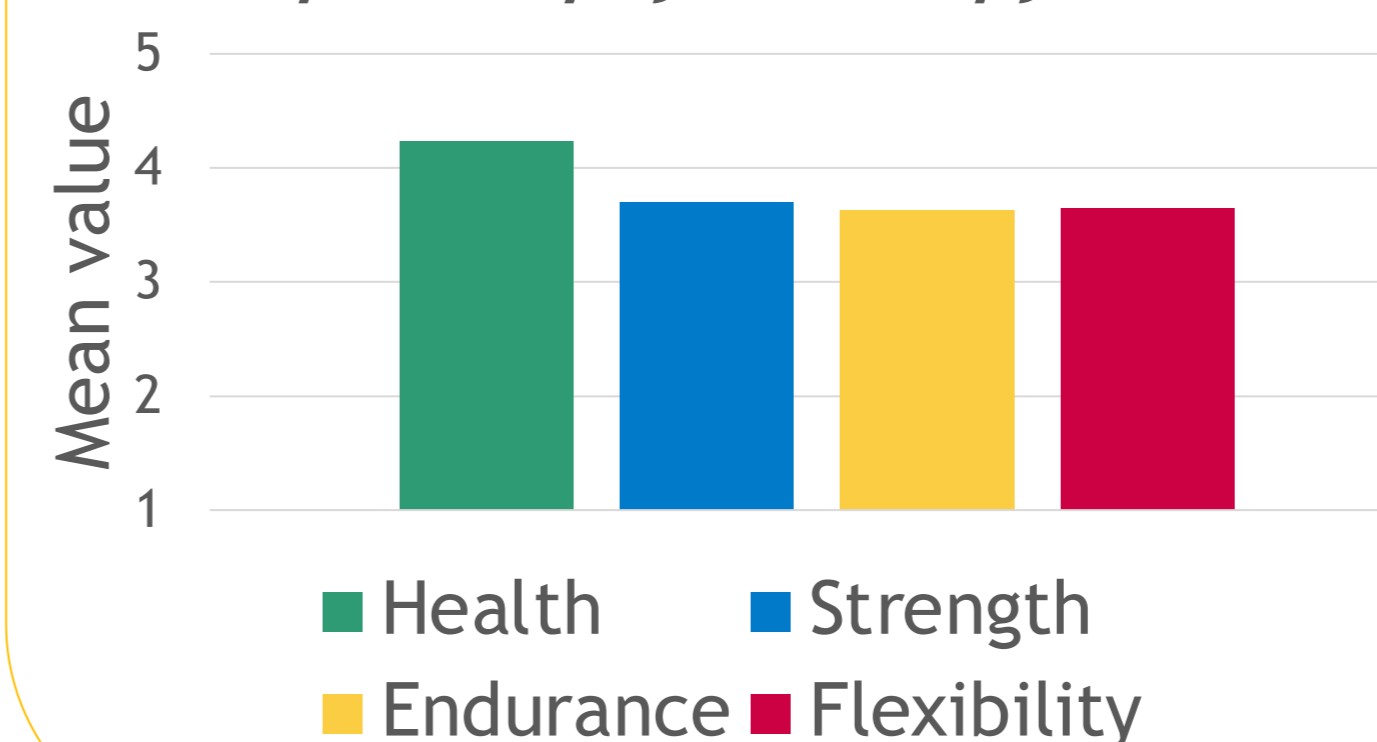


Change in PT after start of treatment

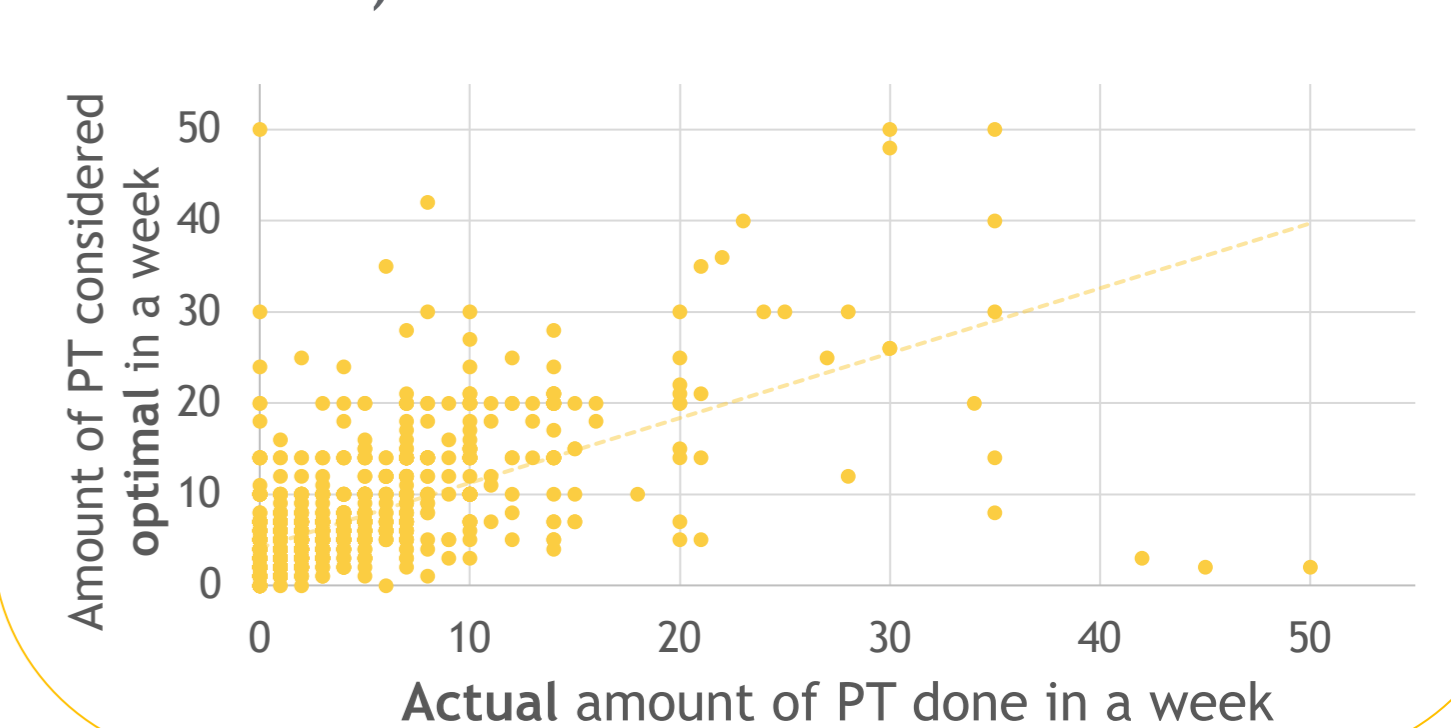


Participants tend to think that physiotherapy is beneficial to them.

Impact of physiotherapy on ...



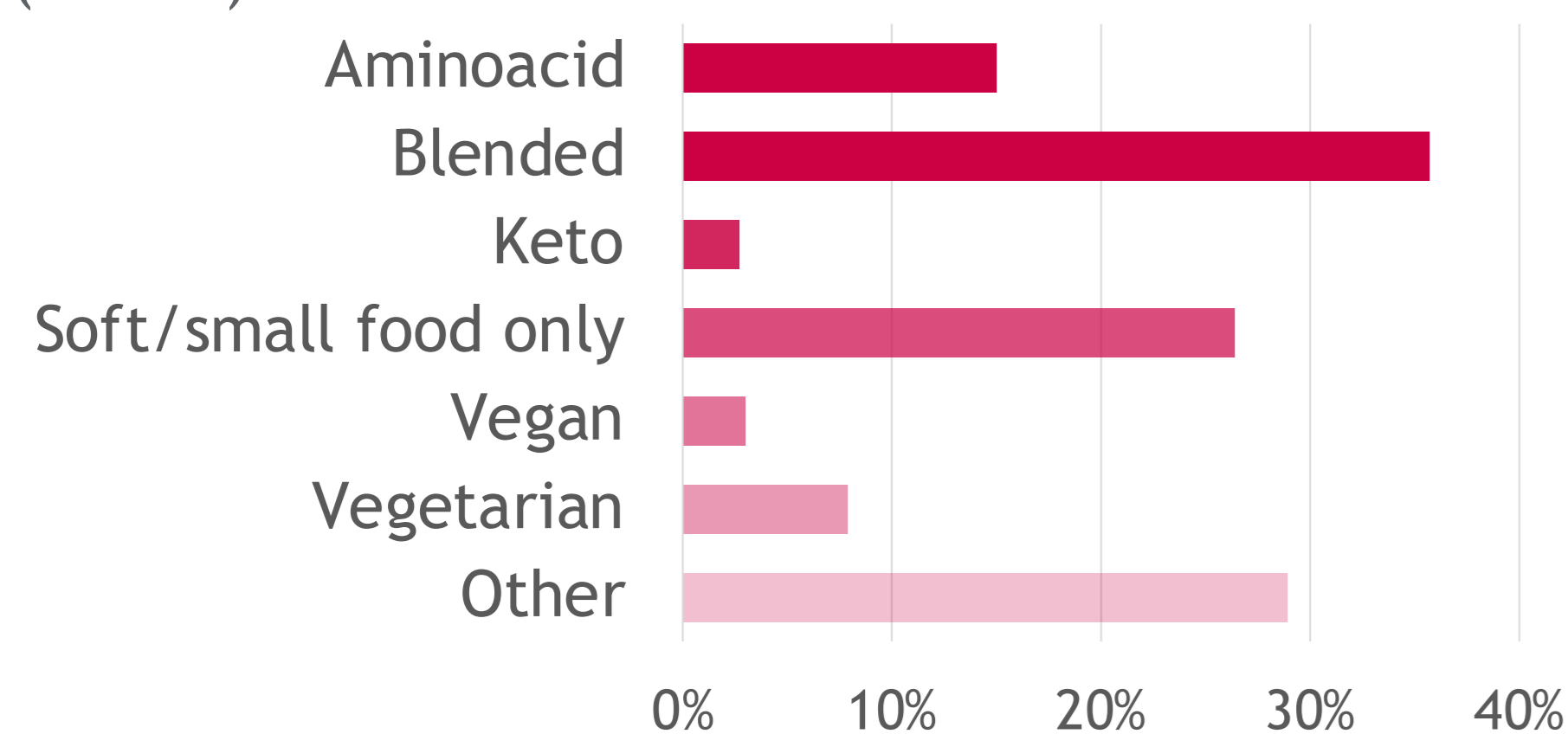
The more PT participants do on average in a week (M = 3.88, SD = 5.05), the more they think they should do (M = 6.98, SD = 5.99, $r_s = 0.59$).



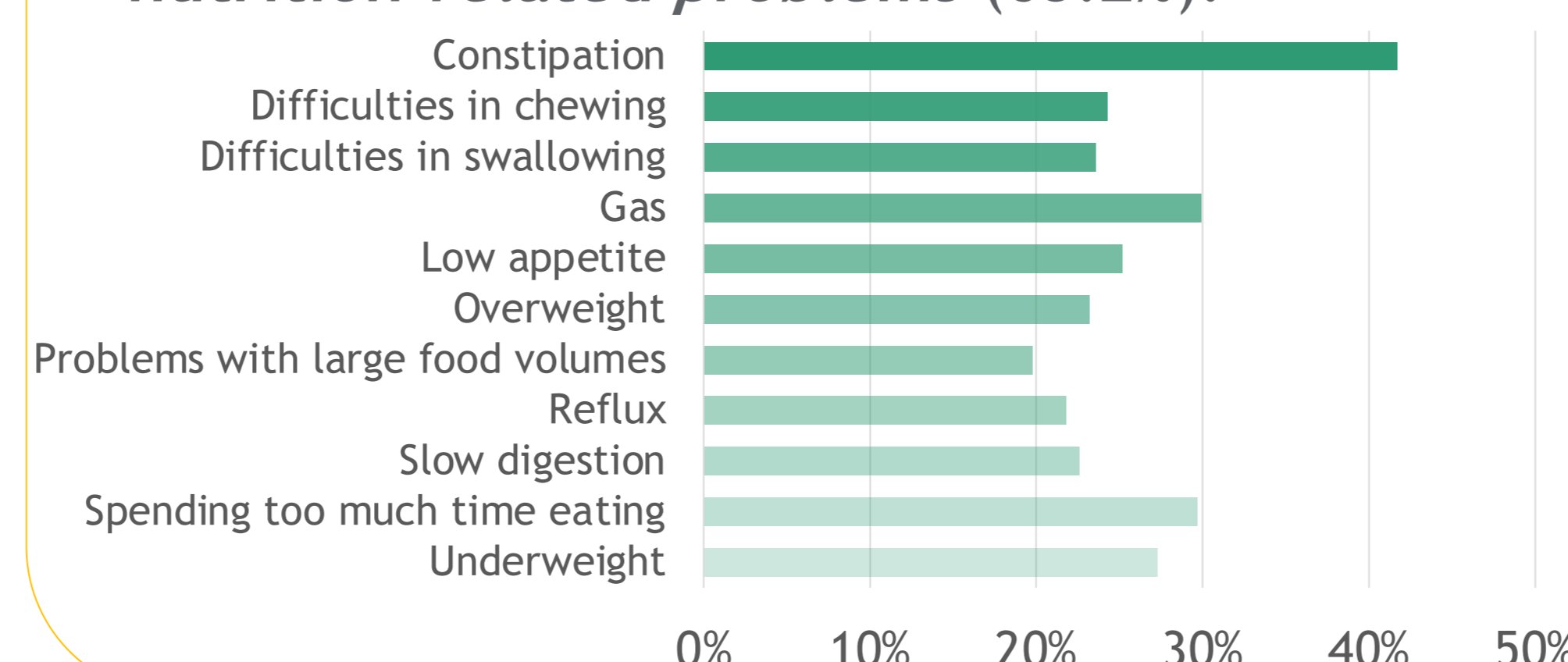
Nutrition



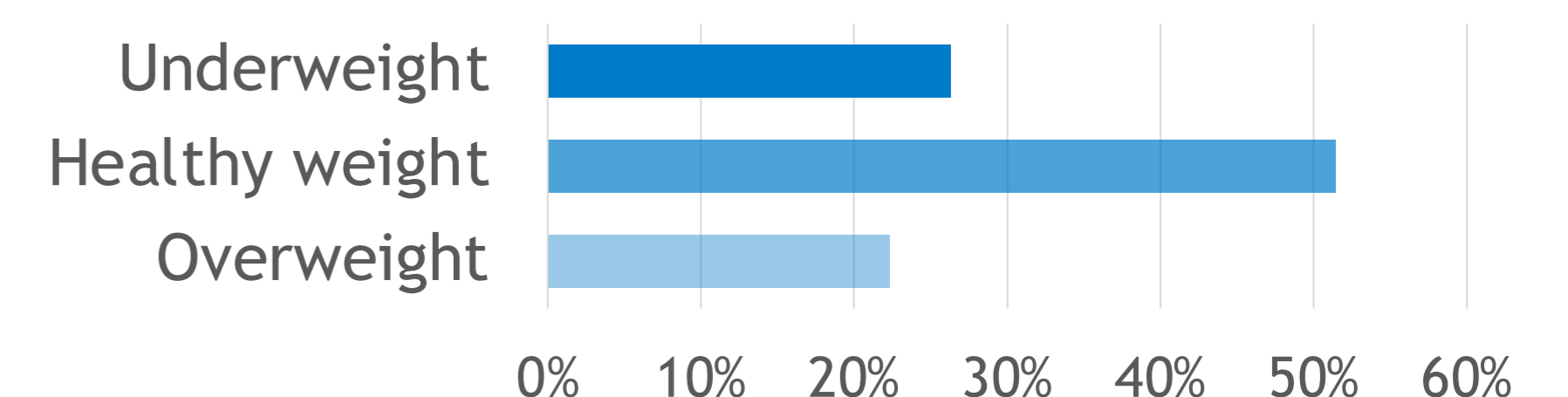
Among the participants who follow a *special diet* (20.3%):



Among the participants who experience *nutrition-related problems* (65.2%):



Participants' *weight* according to their doctor:



Of all participants, 12.4% reported having a *feeding tube* (78.3% *gastrostomy/PEG* and 17.9% *nasogastric tube*). Among them, 69.3% eats only by tube and 30.7% - partly by tube.

Acknowledgments

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evgeniya.vedernikova@sma-europe.eu

