

Unmet care and social care needs of RD patients in Eastern european countries

Results of Rare Barometer Voices surveys:

- Juggling care and daily life, the balancing act of the rare disease community, 2017
- Access to treatment: unequal care for European rare disease patients, 2017

Significant differences between...



Eastern Europe
Belarus
Bulgaria
Czech Republic
Hungary
Poland
Republic of Moldova
Romania
Russian Federation
Slovakia
Ukraine

and...

Other European countries :

Northern Europe	Southern Europe	Western Europe
Denmark	Albania	Austria
Estonia	Andorra	Belgium
Finland	Bosnia and Herzegovina	France
Iceland	Croatia	Germany
Ireland	Greece	Liechtenstein
Latvia	Italy	Luxembourg
Lithuania	Malta	Monaco
Norway	Montenegro	Netherlands
Sweden	North Macedonia	Switzerland
United Kingdom and Northern Ireland	Portugal	
	Serbia	
	Slovenia	
	Spain	

Note: the assignment of countries to specific groupings is based on the United Nations Statistics Division's classification

Greater difficulties in accessing treatments

% of rare disease patients who didn't get the medical treatment they needed in the past 12 months because

Other European countries

Eastern Europe

It was not available where they live

21%



37%

+16

The waiting list was too long

17%



25%

+8

They could not pay for it

14%



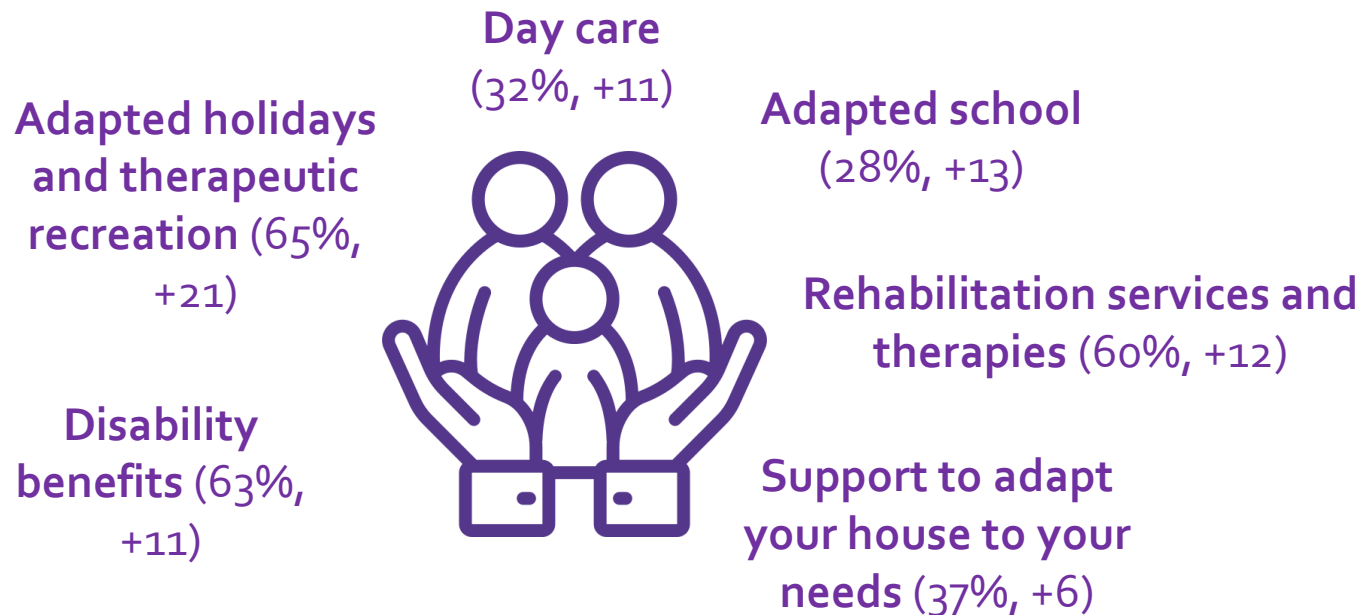
22%

+8

Everyday life impact of the rare disease on families is more important



This can partly be attributed to less support they receive with (% of uncovered needs):



Greater financial pressure on families

Other European countries

Eastern Europe

Costs are high

72%



81%

+9

Costs are hard to manage

61%



76%

+15

% who can't afford it or think it's hard to manage

Home care services
(70%, +12)

Hospital admissions
(29, +9)

Special diet
(58%, +8)

Treatment and medication
(51%, +18)



Appointments with healthcare professionals
(42%, +11)

Respite care
(73%, +16)

Rehabilitation therapies
(61%, +21)

People living with a rare disease from eastern Europe rely more on the internet for information on treatment and care

