

THE DIAGNOSTIC ODYSSEY OF PEOPLE LIVING WITH A RARE DISEASE

Key findings from a Rare Barometer survey

May 2024



17 March
15 June 2022



10,453
respondents
in Europe

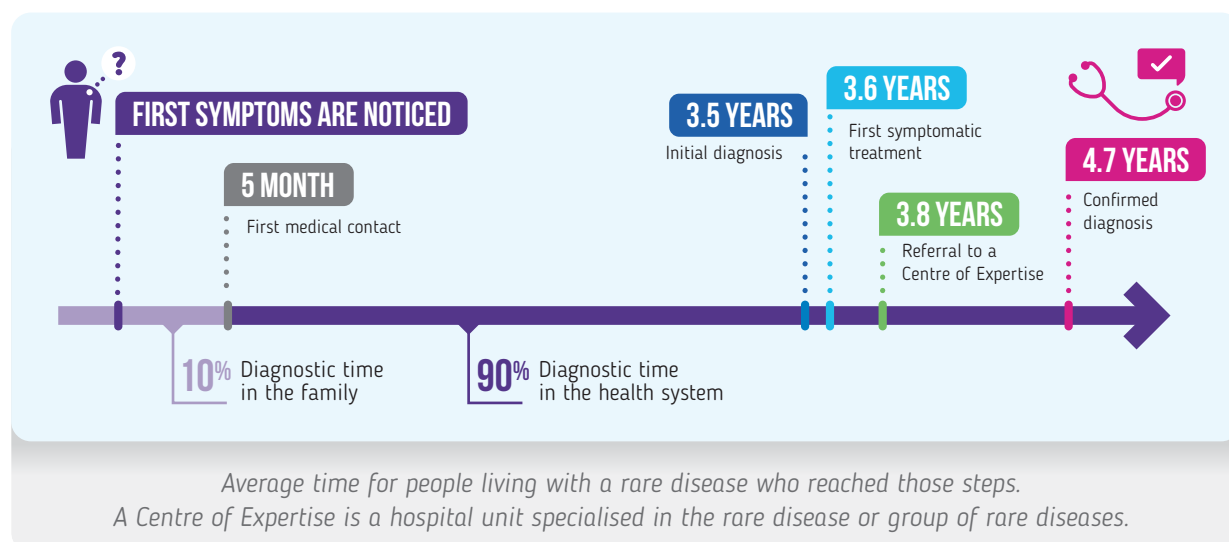


1,675
diseases
represented

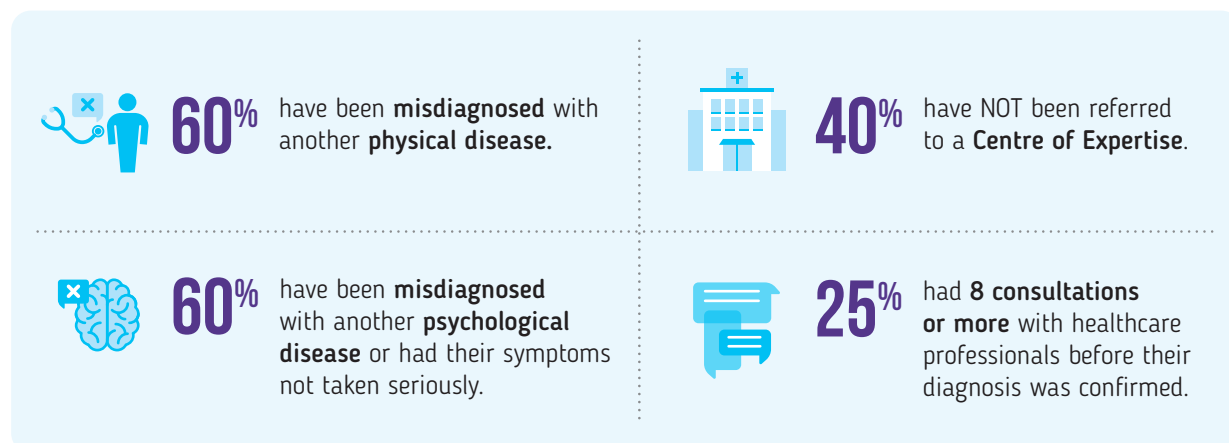


42
countries

Average time between first symptoms and further steps of the diagnostic odyssey



Difficulties associated with the diagnostic odyssey



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Key findings from a Rare Barometer survey

Average number of years between first symptoms and confirmed diagnosis



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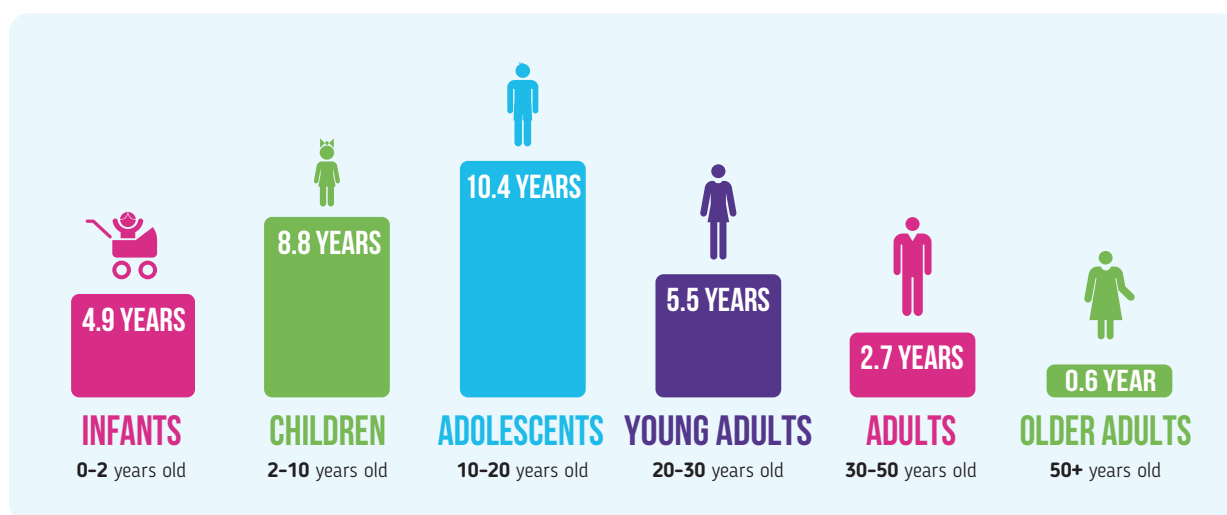


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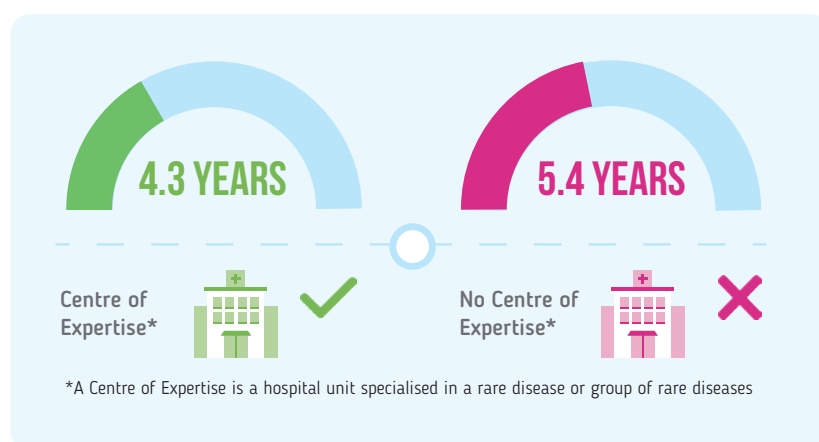
Children and adolescents have a *longer* diagnosis journey than adults



Women have a *longer* diagnosis journey than men



The diagnosis journey is *shorter* when people living with a rare disease are referred to a Centre of Expertise*



30 MILLION

people are living with a rare disease in Europe and 300 million worldwide



NO CURE

for the vast majority of diseases and few treatments available



THANK YOU

to everyone who participated in the survey, and to the Rare Barometer partners!