

THE DIAGNOSTIC ODYSSEY OF PEOPLE LIVING WITH A RARE DISEASE

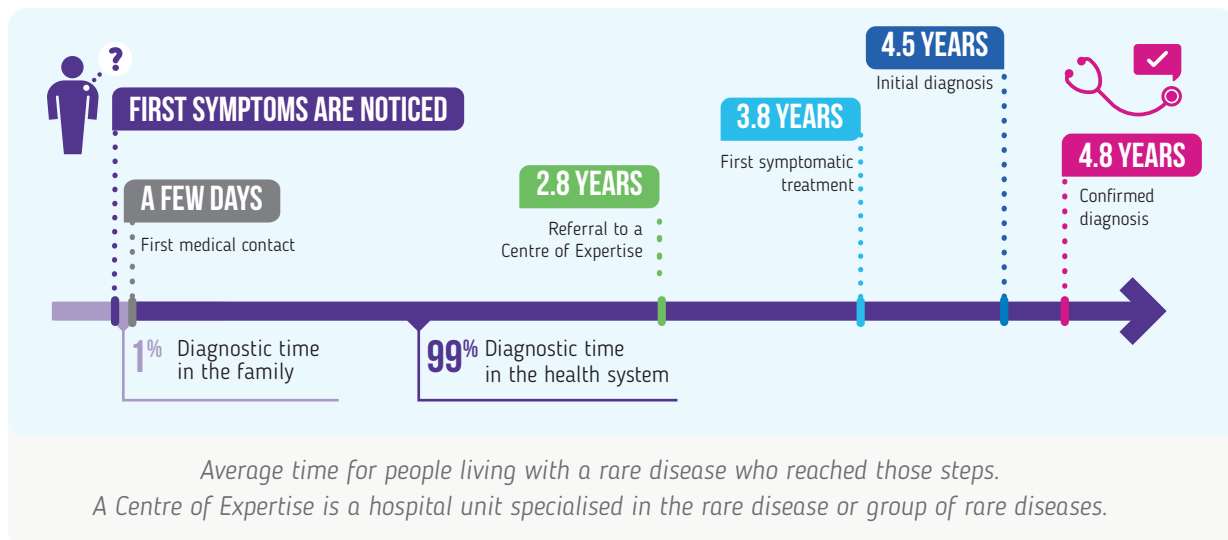
Key findings from a Rare Barometer survey
May 2024

17 March
15 June 2022

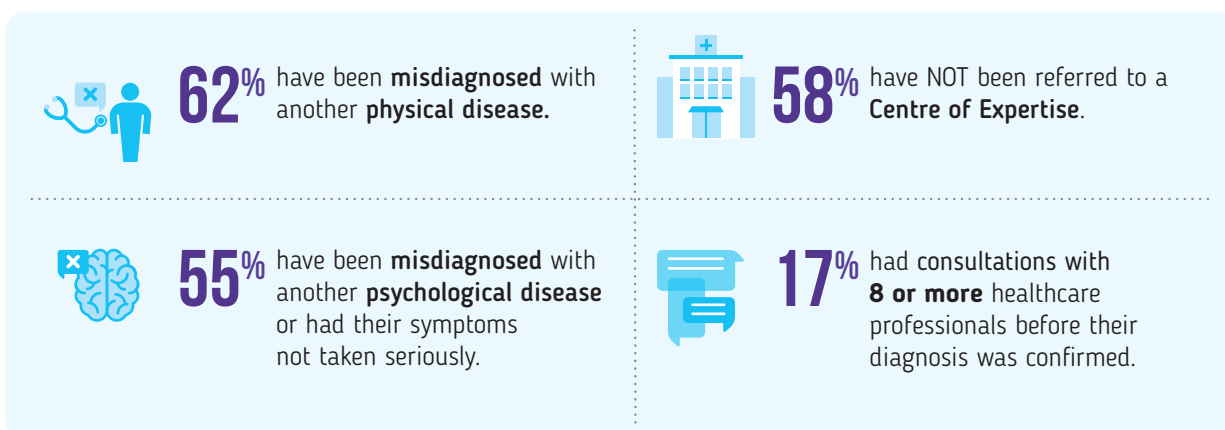
92
participants
in Australia

56
rare diseases
represented

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

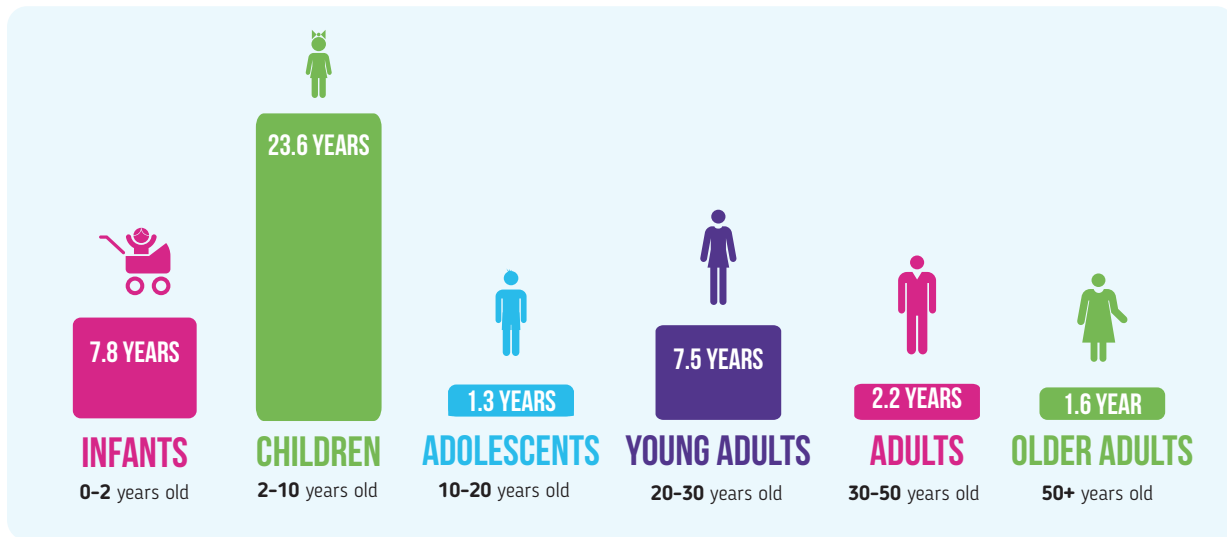
Average number of years between first symptoms and confirmed diagnosis

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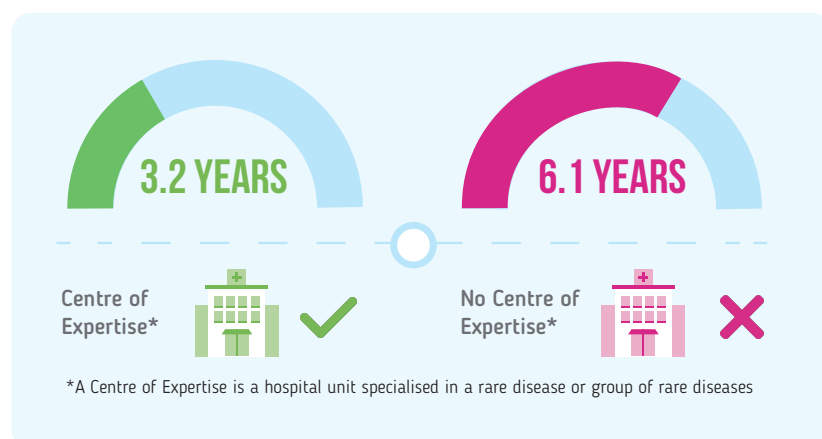
Children have a longer diagnosis journey than adults



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!