THE DIAGNOSTIC ODYSSEY
OF PEOPLE LIVING WITH A RARE DISEASE

Key findings from a Rare Barometer survey

May 2024

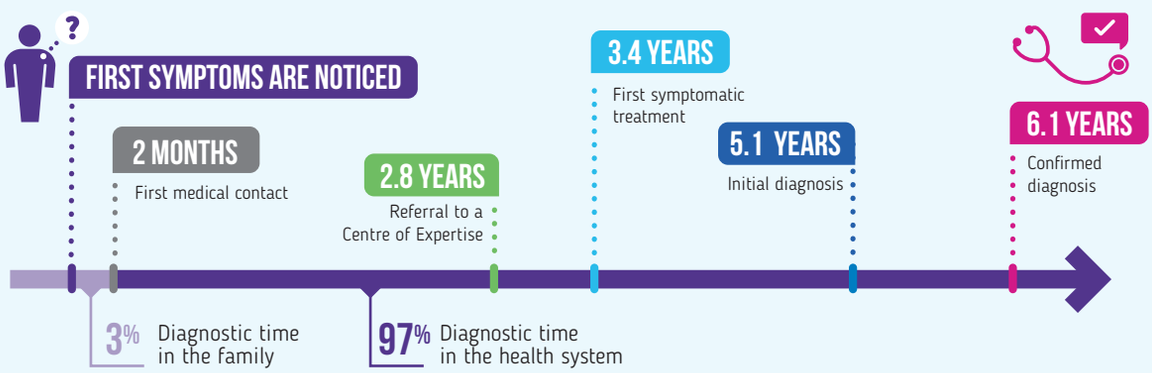
17 March
15 June 2022

105 respondents

66 diseases represented

Ireland

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



Average time for people living with a rare disease who reached those steps.
A Centre of Expertise is a hospital unit specialised in the rare disease or group of rare diseases.

Difficulties associated with the diagnostic odyssey

60% have been **misdiagnosed** with another **physical disease.**

58% have NOT been referred to a **Centre of Expertise**.

72% have been **misdiagnosed** with another **psychological disease** or had their symptoms not taken seriously.

34% had **8 consultations or more** with healthcare professionals before their diagnosis was confirmed.

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!

For more information visit eurordis.org/voices or email rare.barometer@eurordis.org