DetERminants of diagnostic delay

in people living with a RD in Spain

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- **Launched in 2019, the project investigates diagnostic delay to identify its causes, impact and consequences at the health and psychosocial levels, both on the patient and his/her family environment before, during and after the diagnosis is made.**
- **Having included patients´and their families´voice, it aspires to highlight this reality as well as to have an impact on social transformation for the development of research, resources and public policies aimed at minimizing the time and consequences of the diagnosis.**
- **The infographics correspond to the results published in three open access scientific articles. You can check them by clicking or scanning the QR code.**

Diagnosis of rare diseases in Spain

Time elapsed between onset of symptoms and diagnosis

The average time to obtain a diagnosis is approximately 6 years

Diagnosic delay

56.4% of the people with rare diseases have experienced diagnostic delay

Age

People with onset of symptoms between 30-44 years of age are at higher risk of diagnostic delay

Time trend

Since 1960, the time to obtain a diagnosis has been progressively decreasing

Sex

Women have a higher risk of suffering from diagnostic delay

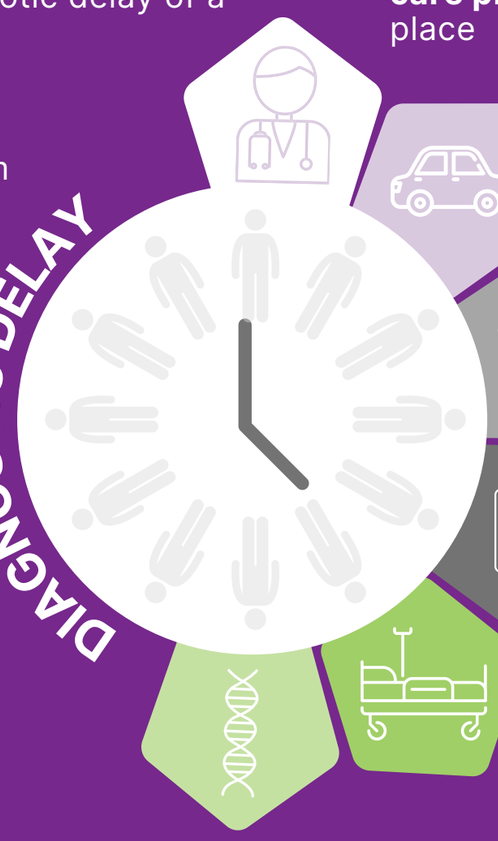
N: 3.349 patients



Clinical Determinants of Diagnostic Delay in Spain

Factors that increase the risk of suffering a diagnotic delay of a RD in Spain

Diagnostic delay: more than 1 year from first consultation (according to IRDIRC goal for 2027)



Visit **to primary health care provider** in the first place

Travel to different hospitals or specialists in their home province and to a different region

Number of specialists visited

Number of clinical tests performed

Surgical interventions

The need for diagnostic genetic testing

N: 1.216 patients

Psycho-social impact of diagnostic delay of a RD in Spain

More than 56% of the people with a rare disease suffer from diagnostic delay

36% of the people with diagnostic delay needed psychological care, compared to 23% of the people diagnosed within 1 year

People with diagnostic delay

Are more **affected** by:

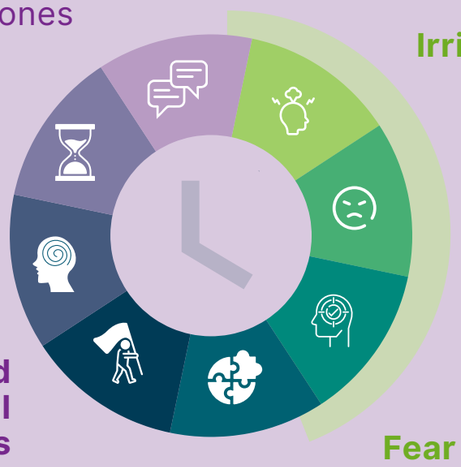
Difficulty in explaining symptoms to loved ones

Difficulty in justifying absences from work or school for medical reasons

Lack of psychological support

Loss of independence and work or educational opportunities

By **obtaining the diagnosis**, they **improved** more in:



Irritability

Frustration

Lack of concentration in day-to-day life

Fear

N: 524 patients

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