

Health-related quality of life in people living with rare diseases

Collaborative study conducted among Share4Rare users.
Age range: 14-82 years.



Perception on general health status

Less than one fifth of those surveyed consider their **health** to be very good or excellent



Bodily pain

40 % of respondents reported moderate to severe **pain** in the past 4 weeks.



Physical functioning



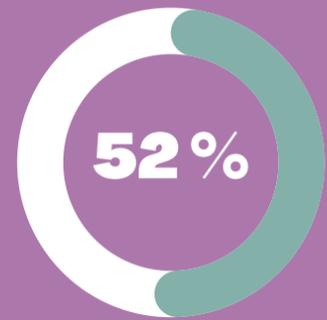
Reported limitations when performing **vigorous-intensity activities**, like running or weight lifting

Role limitations due to physical health



Reduced their working hours or daily activities due to **physical problems***

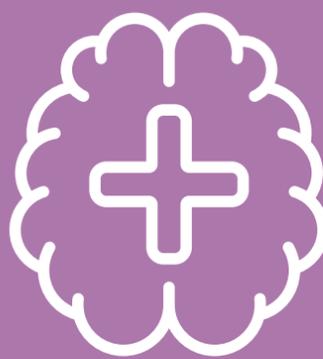
Fatigue



Felt **tired** or that they had **no energy** when performing daily activities*



Reported that **physical and mental health problems** had an impact on their **social activities***



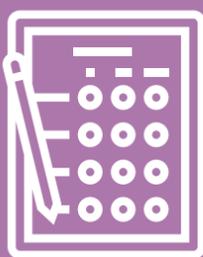
Mental health



Felt **happy** most of the time*



Reduced their working hours or daily activities due to **emotional problems***



These data were obtained through the SF-36 questionnaire from December 17th 2021 to February 15th 2022.



¡JOIN THE STUDY!

* During the past 4 weeks