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
36% of respondents reported physical and mental health problems had an impact on their social activities.*

Role limitations due to physical health
83% reported limitations when performing vigorous-intensity activities, like running or weight lifting.

Fatigue
39% reduced their working hours or daily activities due to physical problems.*

Mental health
52% felt tired or that they had no energy when performing daily activities.*

Fatigue
38% felt happy most of the time.*

Fatigue
30% 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.

* During the past 4 weeks.