

# The Research Project

## Sample & Methodology



**302** People with Narcolepsy

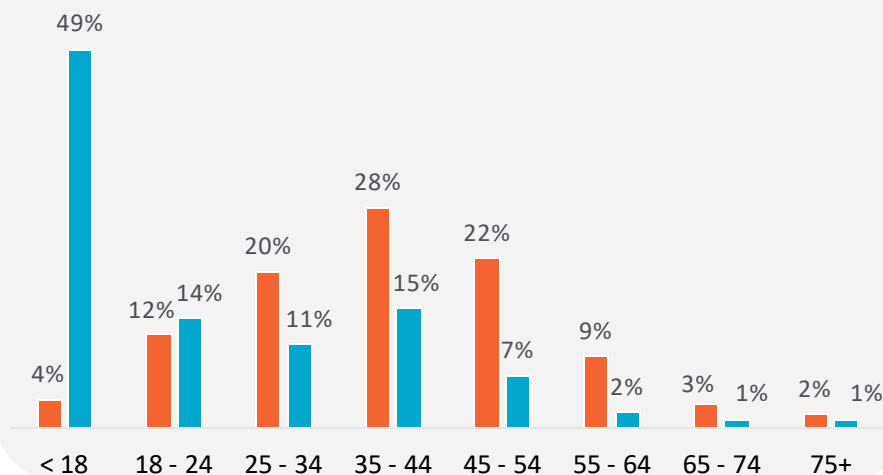


**149** Supporters of People with Narcolepsy  
(parents, partners or other close family and friends)

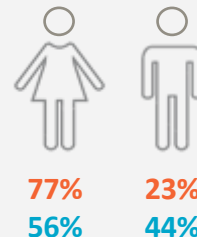
15-minute online survey

■ = People with Narcolepsy    ■ = People with Narcolepsy discussed by their Supporters

## Age



## Gender



## Geography

England **83%** **88%**  
 Scotland **11%** **9%**  
 Wales **4%** **1%**  
 N. Ireland **1%** **1%**  
 Channel Islands **1%**  
 Isle of Man **1%**



## Ethnicity



White **93%** **92%**  
 Multi-ethnic **4%** **4%**  
 Black/ African/ Caribbean/ Black British **2%** **1%**  
 Asian/ Asian British **1%** **1%**  
 Other/ prefer not to say **2%**

### Narcolepsy affects every aspect of daily life...

Data in this section shows the proportion of people who said narcolepsy had a negative impact (scored 1-2 (very negatively / negatively) on a 5 point scale). Some also indicated the condition had a neutral or positive impact

### We have to fight for appropriate medical care...

Data in this section shows the proportion who agreed with statements about their care (scored 4-5 (agree / strongly agree) on a 5 point scale). The time to confirmed diagnosis shows the median value

### Despite this, we battle on...

Data in this section shows proportion of people with narcolepsy who are still in education or employment

### We need help describing our condition to get the support we need...

Data in this section shows proportion of people who agreed they needed more help to describe their condition to get the support that they needed (scored 4-5 (agree / strongly agree) on a 5 point scale)