



2024 KEY FINDINGS IN CURE SMA DATABASES

51% of the SMA community were adults (page 13)

The rates of osteoporosis and chronic pain were higher in the SMA community than the U.S. general population (page 43)

Since 2016, the proportions of individuals living with SMA Type 1 and Unknown SMA Type continued to rise (page 18)

Among individuals diagnosed with hip dysplasia, we observed an increase in the proportion of those with Type 1 SMA after 2017 (page 37)

43% of individuals working part-time reported doing so to stay below an income threshold (page 20)

72% of individuals diagnosed in 2024 were identified by newborn or prenatal screening (page 23)

The average time from diagnosis to first treatment dropped to 18 days for individuals diagnosed in 2024 (page 30)

The average age at first treatment for all individuals diagnosed in 2024 was 23 days (page 25)

The mortality rate of SMA has dropped nearly 80% in the last 10 years (page 44)

Delays in time from diagnosis to treatment for individuals that were diagnosed symptomatically and diagnosed at older ages still remain (page 22)

Pediatric individuals with SMA reported traveling greater distances to their SMA care than adults (page 36)

Approximately half of caregivers reported travel expenses affected them financially

Approximately 75% of the population have been treated with at least one FDA-approved treatment (page 24)

52% of treated individuals have reported receiving an insurance denial for their SMA treatment(s) (page 31)

45% of adults who needed mental health services reported not knowing where to access the needed services (page 39)