Patient Reported Aspects of Becker Muscular Dystrophy from The Duchenne Registry a Comprehensive Registry for Duchenne and Becker Muscular Dystrophy (BMD)

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Data from The Duchenne Registry from Registrants with Becker Muscular Dystrophy
- The Duchenne Registry has been collecting data since 2007 from those affected by Duchenne and Becker
  - Total records over 5000
  - Limited longitudinal data from follow-up entries
  - Patient, family entered data; limited data review possible, so limited duration
- Multiple surveys are collected that focus on different aspects of disease
  - Demographics
  - Diagnosis: age, symptoms at onset
  - Muscle function: ambulation status, use of supportive devices
  - Genetic testing, family history
  - Corticosteroid use
  - Pulmonary, cardiac, bone and behavior

Data Available in the Duchenne Registry
- Data set through May 2022
  - Unique registrants with Becker: 334 total
  - Registrants submitted: 378
- This analysis includes all countries

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