The primary objective of this data is to characterize the disease costs incurred by ALS patients covered by Medicare or commercial insurance before diagnosis. To determine the ALS costs before and after diagnosis for patients already under Medicare coverage, we employed Kaplan-Meier Sample Average (KMSA) to analyze the data. We also analyzed both pure Medicare and commercial data separately, using Medicare and commercial costs; out of pocket costs likely remained the same.

### Methods

**Data Sources:**
- Medical claims databases containing patient information and costs.
- Demographic and clinical information obtained from ALSOnet, a registry.
- Access to Mayo Clinic’s electronic health record system.
- Randomly sampled Medicare data from 5% of all Medicare Part A and Part B claims processed nationally from 2008 to 2013.
- Commercial insurance data obtained from Tuens HealthMarkets, containing approximately 50 million members currently insured.

**Case Selection:**
- ALS cases were identified as:
  - All cases with at least one claim with ICD9 code 744.0.
  - All cases with a diagnosis code (ICD9 code 744.0).
  - Pure Medicare cases: diagnosed in 2008 through 2013 and covered by Medicare.
  - Commercial cases: diagnosed in 2008 through 2013 at Mayo Clinic.
  - ALS patients identified from the Tuens HealthMarkets commercial database.

**Disability Milestone Definition:**
- The following codes in the claim data were used to determine when patients achieved the disability milestones.

### Results: Demographic Data

<table>
<thead>
<tr>
<th>Number of Cases</th>
<th>Pure Medicare</th>
<th>Commercial Insurance</th>
</tr>
</thead>
<tbody>
<tr>
<td>368</td>
<td>344</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Mean Age (SD)</th>
<th>Pure Medicare</th>
<th>Commercial Insurance</th>
</tr>
</thead>
<tbody>
<tr>
<td>75.3 (6.71)</td>
<td>54.3 (7.98)</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Male (%)</th>
<th>Pure Medicare</th>
<th>Commercial Insurance</th>
</tr>
</thead>
<tbody>
<tr>
<td>57.8%</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Average Months after Index Date (SD)</th>
<th>Pure Medicare</th>
<th>Commercial Insurance</th>
</tr>
</thead>
<tbody>
<tr>
<td>14.1 (9.9)</td>
<td>13.5 (6.8)</td>
<td></td>
</tr>
</tbody>
</table>

### ALS Monthly Costs: Commercial Insurance

- **Kaplan-Meier Sample Average (KMSA) was employed to analyze the data.**
- **To avoid complications from the often rapid transition from commercial insurance to Medicare, Medicare data were analyzed separately.**
- **For pure Medicare cases, Kaplan-Meier Sample Average (KMSA) was employed to analyze the data.**

### Total Costs to Disability Milestones: Pure Medicare

- **The cumulative cost from index date to disability milestones increased substantially with the severity of physical impairment in Medicare cases.**

### Discussion

- **This analysis only includes Medicare and commercial costs; out of pocket costs likely increased the economic burden significantly.**
- **The increasingly important roles of risk adjusters, reinsurance and pooling were apparent.**
- **Limited duration of follow-up makes many of our conclusions tentative.**
- **This analysis only includes Medicare and commercial costs; out of pocket costs likely increased the economic burden significantly.**
- **It will be important to explore whether disease stage at diagnosis, demographics and disability milestones influence costs.**
- **Some trends were observed during the coverage transition in Medicare.**

### Conclusions

- **Medical costs in the diagnosis month were significantly higher than other months.**
- **Costs started to increase exponentially within about 8 months before the index month for both Medicare and commercial cases.**
- **Costs in the month following the index month were less than the costs in the index month, but monthly costs increased after that.**
- **Each insurance program reduced its costs from index month for both Medicare and commercial cases.**
- **No trend in costs was observed during the coverage transition to Medicare.**
- **Approximately 3% of ALS patients are already receiving supportive services for disabilities at the time of diagnosis.**
- **Medical costs increased rapidly and substantially with each disability milestone.**