

# Skeletal Muscle Activity and Resource Tool for Sporadic Inclusion Body Myositis: Characterization of Resource Utilization and Financial Burden Experienced by sIBM Patients

Victoria Barghout,<sup>1</sup> Carla DeMuro,<sup>2</sup> Mark Price,<sup>2</sup> Sandra Lewis,<sup>2</sup> Brian Tseng<sup>3</sup>

<sup>1</sup>VEB HealthCare, Morristown, NJ, United States;

<sup>2</sup>RTI Health Solutions, Research Triangle Park, NC, United States;

<sup>3</sup>Novartis Pharmaceuticals, East Hanover, NJ, United States

## BACKGROUND

### Sporadic Inclusion Body Myositis (sIBM)

- Sporadic inclusion body myositis (sIBM) is a progressive, idiopathic inflammatory myopathy characterized by atrophy and weakness of proximal and distal muscle groups.<sup>1</sup>
- Atrophy of the quadriceps, wrist, and finger flexor muscles, as well as dysphagia are clinical hallmarks of the disease and result in significant functional disabilities with progression.<sup>1</sup>
- sIBM primarily affects individuals aged 50 years and older and is more common in men than in women.
- Symptoms worsen over time, causing most patients to eventually lose ambulatory status and the ability to perform many routine activities of daily living.<sup>2,3</sup>
- In addition to the physical impact of sIBM, this disease is associated with a socioeconomic burden as progressive weakness results in the need for assistive devices, loss of independence, and need for supportive care. However, little information is available on the socioeconomic burden of sIBM in the United States (US) or elsewhere.
- As health care resource utilization costs are more likely to be nonreimbursable and not captured within the context of studies focused on insurance claims databases, collection of costs associated with sIBM is needed to determine the true economic burden of disease.

### Skeletal Muscle Activity and Resource Tool—Sporadic Inclusion Body Myositis (SMART-sIBM)

- The SMART-sIBM is a novel tool developed to capture patient-reported resource utilization and health care costs associated with sIBM via a web-based interface or on paper.
- The tool was developed based on three main sources:
  - Patient interviews
  - Existing generic health care resource utilization measures
  - Expert input (clinicians and health economists)
- The SMART-sIBM was developed from a US perspective; cross-cultural adaptations are possible.
- The tool consists of 19 multiple choice items with open-ended questions to capture costs, as well as the impact of sIBM on work for pay.
- Participants provide self-reported information for the past 6 months.

## OBJECTIVE

- To describe resource utilization in a US-based sample of patients with sIBM using the SMART-sIBM tool.

## METHODS

- A repeated cross-sectional study was conducted with patients at The Myositis Association (TMA) 2013 and 2014 annual patient conferences (n = 102).
  - Registered participants with a clinical diagnosis of sIBM were invited to participate.
- Participants completed either a paper or web-based version of the SMART-sIBM.
- A subset of participants (n = 31) participated in both cross-sectional assessments.

## RESULTS

### Patient Demographics (Table 1)

- Overall, mean age was 67.2 years (range 49-88), and most (62%) participants were male, white (94%), and well educated (72% with at least some college).
- The mean number of years since receiving a diagnosis of sIBM was 5.29 (standard deviation [SD]: 4.3; Median: 5.0; Min-Max: 0-17).
- The mean number of years since first experiencing symptoms of sIBM was 11.27 (SD: 6.4; Median: 11.0; Min-Max: 1.35).

### Limitations due to sIBM (Figure 1 and Figure 2)

- Approximately 94% of participants reported increased muscle weakness as a result of their sIBM, and nearly 85% reported a decrease in the ability to perform certain daily activities. More than three-quarters of participants reported an impact on their walking ability.
- Approximately one-third of participants reported being ambulatory without an assistive device; 37% noted use of an aid/brace; 17% used power mobility for long distances; 7% used power mobility most of the time; 4% noted an inability to walk or stand.

### Health Care Visits (Table 2)

- Thirty-seven patients (40%) of patients visited a general practitioner in the past 6 months for their sIBM (mean [SD] = 1.9 [2.0]).
- Sixty-one patients (62%) visited a specialist in the past 6 months for their sIBM (mean [SD] = 2.0 [1.7]).
- More than one-third (36%) of participants required paid help with household tasks, and 60% relied on help from unpaid caregivers (87% spouse). Nearly half (42%) reported a change in job status because of sIBM-related functional limitations.
- Approximately 10% of patients reported scheduled visits to the hospital for procedures related to their sIBM. Less than 10% of patients reported the use of other care options.
- Average number of falls per month and health care visits because of falls was <1 (range 0-4) and 0.71±1.8 (range 0- 12), respectively.

### Education and Job Status (Figure 3)

- Nearly two-thirds (63.9%) of participants reported having either an undergraduate or postgraduate university degree.
- When asked about their current work status, more than half of participants (55.1%) reported that they were retired; 20% stated they were employed full-time; 10% indicated part-time employment; and 10% indicated their current work status was permanently disabled.
- Approximately 42% of patients reported a job status change had occurred due to their sIBM. Of the 40 patients indicating a status change, 88% reported that they were employed/self-employed or a full-time student prior to the status change.
  - The average age at the time of the change in job status for these 40 patients was 60.5 years (SD = 6.8).

### Other Costs (Table 3)

- A majority of patients (68.4%) reported that they had to make changes to their house, apartment, or car because of their sIBM, resulting in a mean nonreimbursed cost of \$148,347 (range: \$0 to \$7,000,000).
- Over-the-counter products were purchased by 73.2% of participants, representing \$2,112.79 of the total nonreimbursable costs for those purchases.
- Seventy-seven percent of patients reported having to purchase special equipment, devices, or aids. The average total nonreimbursed cost of these purchases was \$9,974 (range: \$0 to \$300,000).
- More than half (60%) of participants had a nonprofessional, nonpaid caregiver. Of the 57 participants who had a caregiver, about 88% of those caregivers were spouses.

Table 1. Patient Demographics

Characteristic	(n = 102)
<b>Age (years)</b>	
Mean (SD)	67.20 (8.0)
Median, Min-Max	67.5, 49-88
<b>Group, n (%)</b>	
< 65 years	35 (35.7)
65-69 years	24 (24.5)
70-74 years	22 (22.4)
75-79 years	12 (12.2)
≥ 80 years	5 (5.1)
<b>Sex, n (%)</b>	
Male	63 (61.8)
Female	39 (38.2)
<b>Height (inches)</b>	
Mean (SD)	67.90 (4.2)
Median, Min-Max	67.8, 61-78
<b>Weight (pounds)</b>	
Mean (SD)	176.57 (39.6)
Median, Min-Max	170.0, 107-285
<b>Body mass index</b>	
Mean (SD)	26.76 (4.8)
Median, Min-Max	26.4, 20-43
<b>Ethnicity, n (%)</b>	
White	94 (95.9)
African American, American Indian, Asian, Hispanic, Pacific Islander, other	2 (2.0)

Figure 1. Limitations due to sIBM

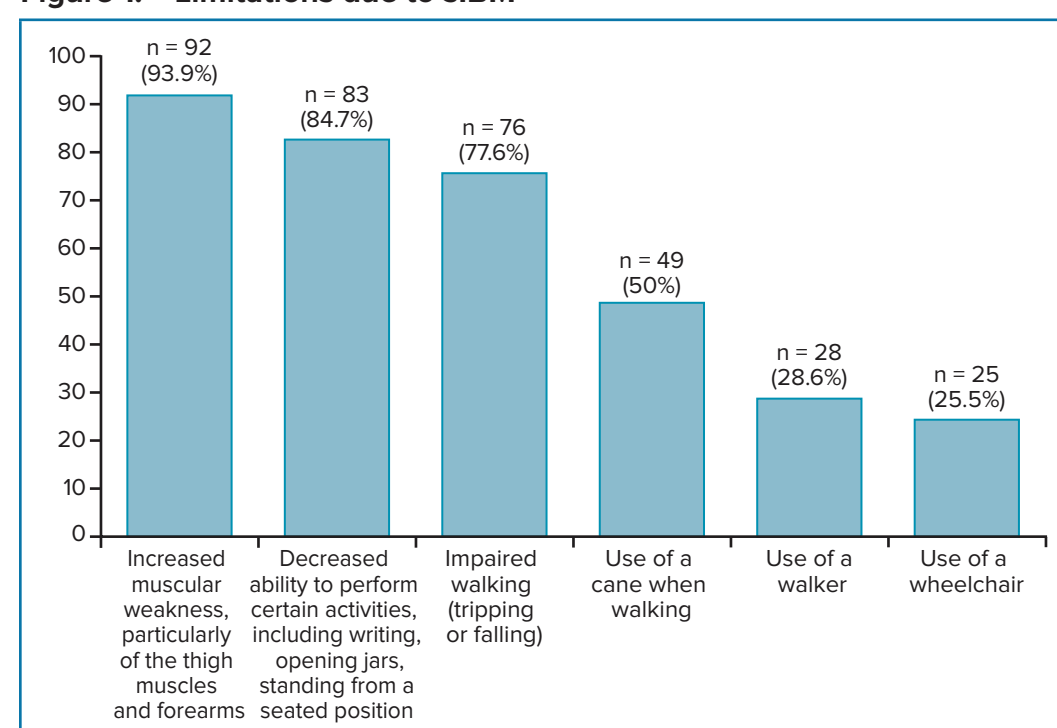


Figure 2. Ambulatory Status

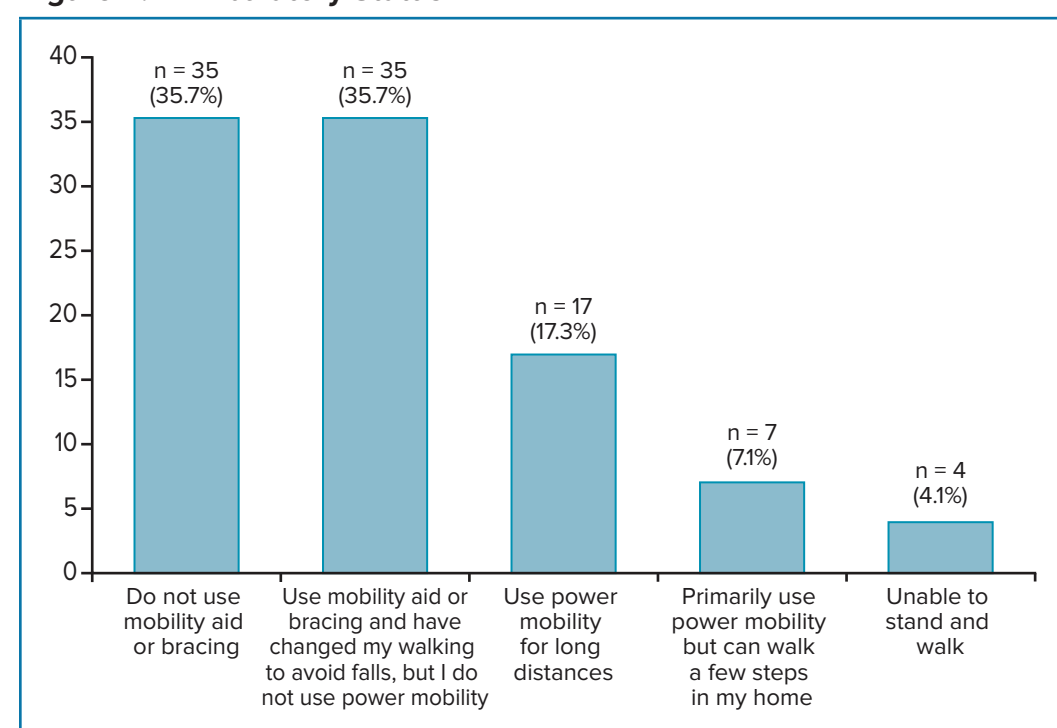


Table 2. Health Care Visits

Number of Visits in the Past 6 Months	n/N (%)	Median Minimum-Maximum
General practitioner	37/94 (39.4)	1, 1.0-12.0
Specialist	61/98 (62.2)	1.0, 0.0-12.0
Home visits by a nurse	7/97 (7.2)	7.0, 2.0-12.0
Home visits by a physical therapist or occupational therapist	3/97 (3.1)	4.5, 3.0-6.0
Nurse	6/97 (6.2)	1.5, 1.0-6.0
Urgent care facility	6/97 (6.2)	1.0, 0.0-2.0
Emergency visits to a hospital	8/97 (8.2)	1.0, 1.0-3.0
Scheduled visits to the hospital for procedures related to your sIBM	10/97 (10.3)	1.0, 1.0-4.0
Counseling or emotional support for sIBM	8/96 (8.3)	3.5, 2.0-12.0

Figure 3. Highest Level of Education

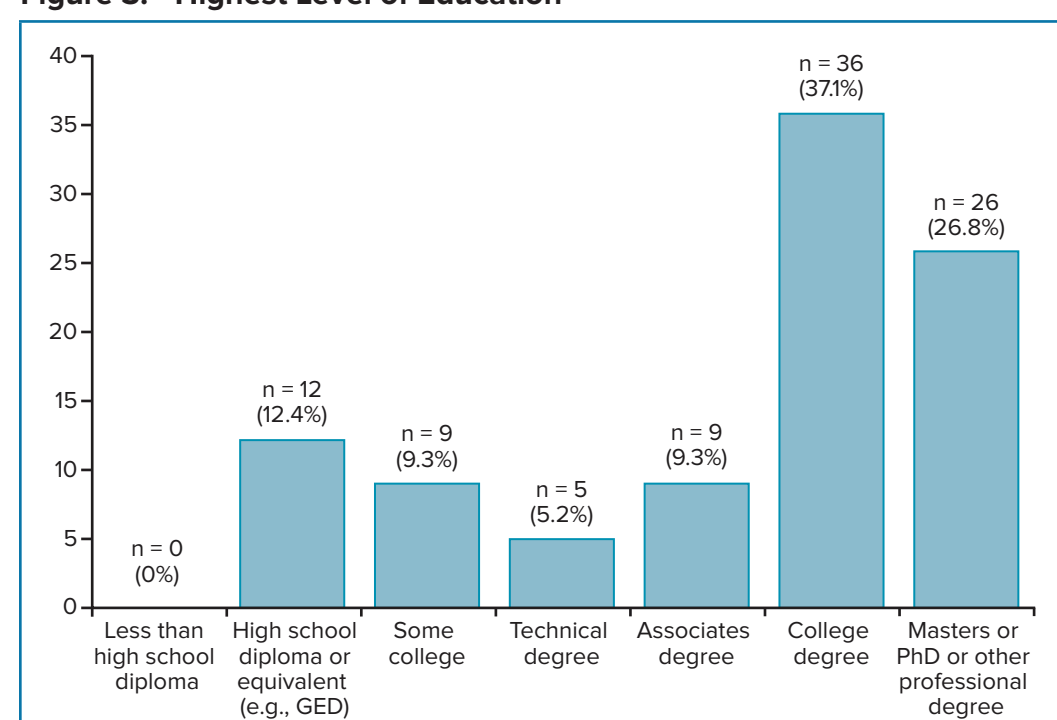


Table 3. Other Costs

SMART-sIBM Question	n (%)	Median Minimum-Maximum
Source of payment for majority of health care costs	n = 98	
Self-pay	7 (7.1)	
Medicare	22 (22.4)	
Medicaid	1 (1.0)	
Private insurance	35 (35.7)	
Combination of Medicare and private insurance	33 (33.7)	
Physician-prescribed drugs in the past 6 months for sIBM	n = 98	
No	77 (78.6)	
Yes, approximate nonreimbursed costs for these treatments	21 (21.4)	\$33.50, \$0.00-\$4,200.00
Changes to house, apartment, or car due to your sIBM since diagnosis	n = 98	
No	31 (31.6)	
Yes, approximate total nonreimbursed cost for these purchases	67 (68.4)	\$4,000.00, \$0.00-\$7,000,000.00
Purchase of special equipment, devices, or aids since diagnosis with sIBM	n = 98	
No	23 (23.5)	
Yes, approximate total nonreimbursed cost for these purchases	75 (76.5)	\$1,000.00, \$0.00-\$300,000.00
Change of residence due to sIBM-related disabilities since diagnosis of sIBM	n = 98	
No	74 (75.5)	
Yes	24 (24.5)	
Nonreimbursed costs due to changing residence	n = 24	
No	3 (12.5)	
Yes, approximate total nonreimbursed costs	21 (87.5)	\$20,000.00, \$500.00-\$365,000.00
Details of move	n = 24	
Another private residence with spouse or family	17 (70.8)	
A retirement community	3 (12.5)	
Assisted living facility	0 (0)	
Other	4 (16.7)	
Professional (paid) help around your home for household tasks due to your sIBM in the past 6 months	n = 98	
No	62 (63.3)	
Yes, approximate amount for these costs	36 (36.7)	\$600.00, \$0.00-\$120,000.00
Nonprofessional, nonpaid caregiver	n = 95	
No	38 (40.0)	
Yes	57 (60.0)	
Primary (nonprofessional, nonpaid) caregiver	n = 32	
Spouse	28 (87.5)	
Other family member	4 (12.5)	
Friend/neighbor	0 (0)	

HCRU = Health Care Resource Utilization; Q1 = 25th percentile; Q3 = 75th percentile.

## CONCLUSIONS

- This study provides socioeconomic data for the first time in a US-based sample of mostly ambulatory patients with sIBM, indicating significant burdens experienced by patients.
  - Costs of loss of independence and mobility are well documented through utilization of the SMART-sIBM.
- The SMART-sIBM provides a unique look at patients' disease burden with respect to resource utilization due to their sIBM.
  - Changes or modifications to living arrangements, homes, or vehicles to accommodate sIBM-related disabilities
  - Need to purchase other special equipment
  - Paid household help, as well as unpaid caregivers such as spouse, children, friend, or neighbor
  - Frequent health care visits
  - Impact on work for pay, including indication of early retirement

## REFERENCES

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## CONTACT INFORMATION

**Carla DeMuro, MS**  
Head, Patient Reported Outcomes

**Mark Price, MA, Med**  
Senior Director, Surveys and Observational Studies

RTI Health Solutions  
200 Park Offices Drive  
Research Triangle Park, NC 27709 US

Phone: +1.484.597.0159  
E mail: demuromercon@rti.org

