

# Characterizing the Impact of Work Productivity of Patients With DMD and Their Caregivers: A Societal Perspective

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Key Findings

Reductions in tax revenue

98.8%

Due to the progressive nature of Duchenne muscular dystrophy (DMD) and early mortality, patients with DMD receiving standard of care (SoC) experience a near total loss of income compared with the US male population, resulting in reductions in tax revenue

13.9%

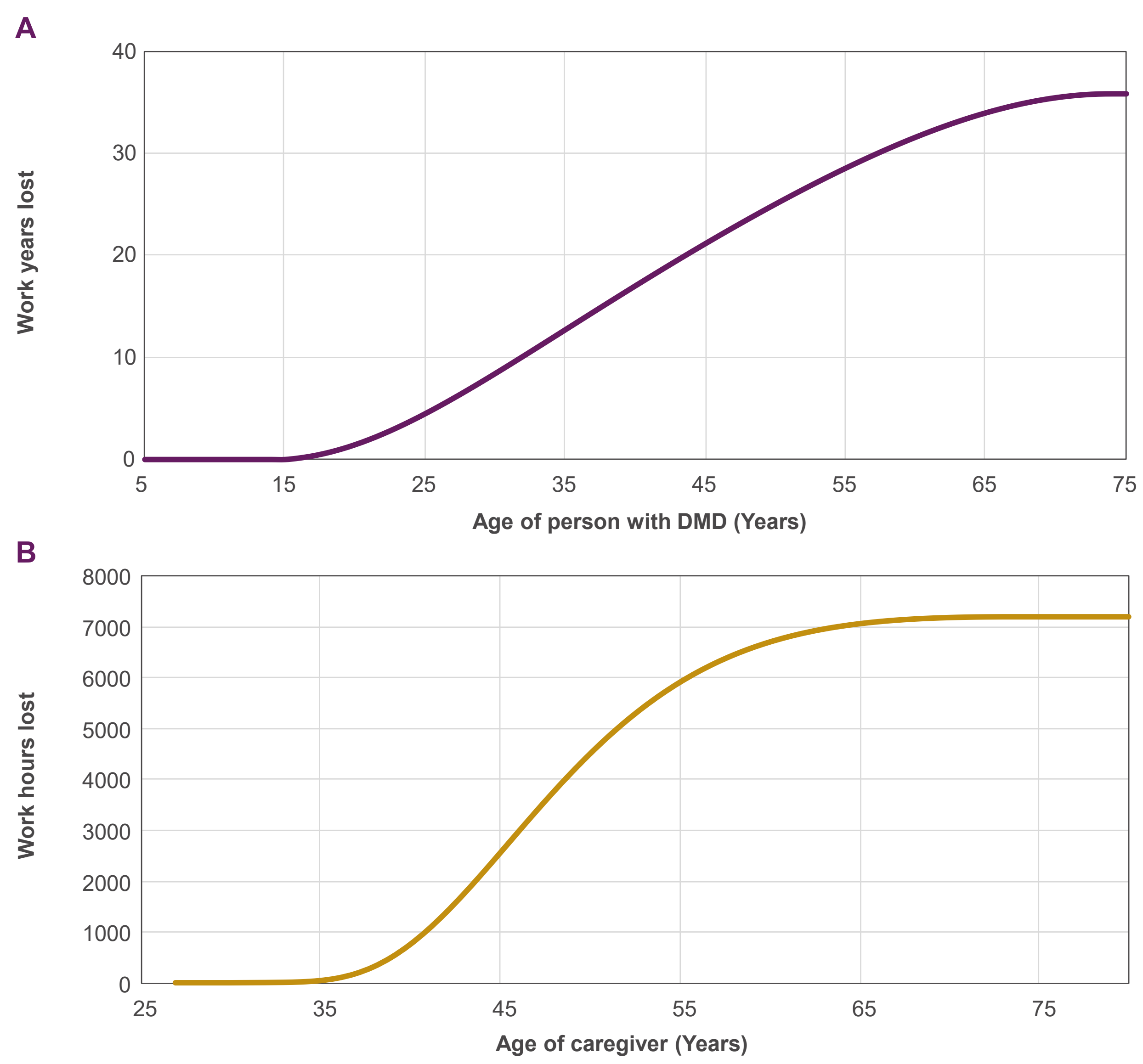
Caregiver income is also impacted, resulting in further losses in tax revenue

Losses from tax revenue reach beyond patients with DMD and their caregivers, impacting society at large

## Background

- Duchenne muscular dystrophy (DMD) is a rare neuromuscular disease occurring primarily in males, with symptoms presenting most commonly in the first years of life, resulting in progressive muscle weakness, loss of functional ability in the upper and lower body, and mortality in the third decade of life<sup>1-3</sup>
- Due to the severity of DMD and premature mortality, individuals with DMD have reduced work opportunities compared with a typical US male<sup>4,5</sup>
  - Similarly, due to the evolving needs of individuals with DMD, caregivers experience diminished work productivity as they reduce working hours or leave the workforce altogether<sup>4-7</sup>
- Previous studies have revealed significant disparities in workforce participation and lifetime earned income between: a) patients with DMD receiving standard of care (SoC) and the general US male population, and b) caregivers of patients with DMD and the US general population<sup>4,8</sup> (**Figure 1**)
- Although patients and caregivers endure the primary burdens of DMD, when conducting value assessments, it is important to consider secondary societal burdens such as loss of tax revenues

**Figure 1** Cumulative loss of work by age for (A) patients with DMD (in years) and (B) DMD caregivers (in hours)<sup>4</sup>



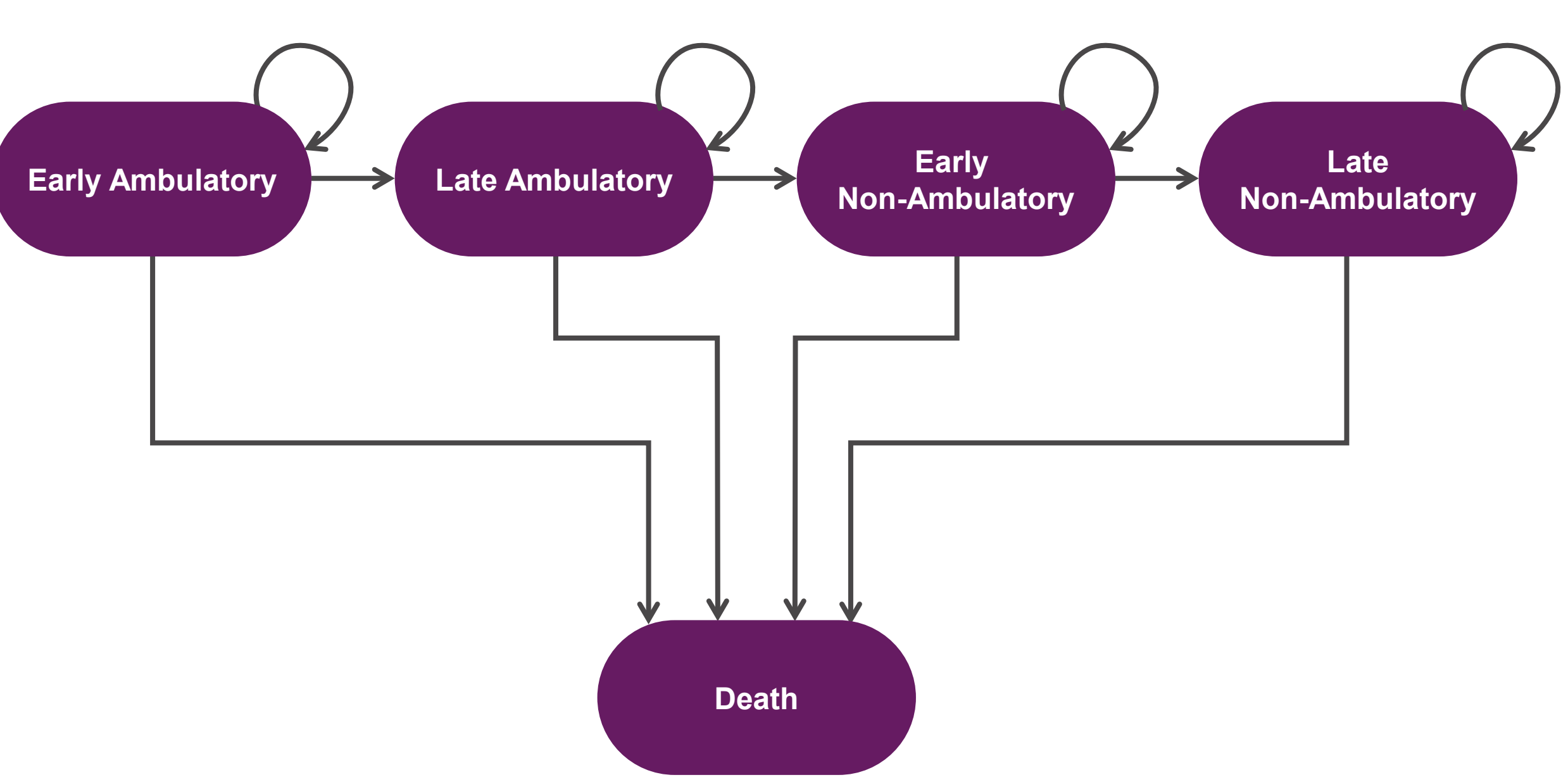
## Objective

- To quantify the societal impact of DMD on unrealized tax revenue due to lost workforce participation and lifetime income in the context of informing value framework analyses

## Methods

- A five-state partitioned survival model (**Figure 2**) was developed to assess a homogenous cohort of 4-year-old early ambulatory patients with DMD
- DMD progression on SoC (corticosteroids and medical management) was obtained from published literature<sup>1,9-11</sup>
- Work opportunity and productivity for the early ambulatory cohort (receiving SoC) was estimated from age-based median salaries for US males, adjusted for mortality and employment rates; a similar approach was taken for caregiver (age, ≥31 years) work time loss estimates relative to the general population<sup>12</sup>
- Lifetime net tax contributions based on the US tax system were incorporated into the model, which included total effective federal, state, and local tax rates for different income percentiles calculated from the average income each year (total tax rate range: 20.4% to 34.4%)<sup>13</sup>
- Tax contributions were compared for patients receiving SoC vs the general US male population, and caregivers of patients receiving SoC vs the general US population (male and female)
- Revenues from caregivers were based on taxation of both employment and retirement income
- A 3% annual discount rate and 2.8% annual salary growth rate was applied to potential earnings

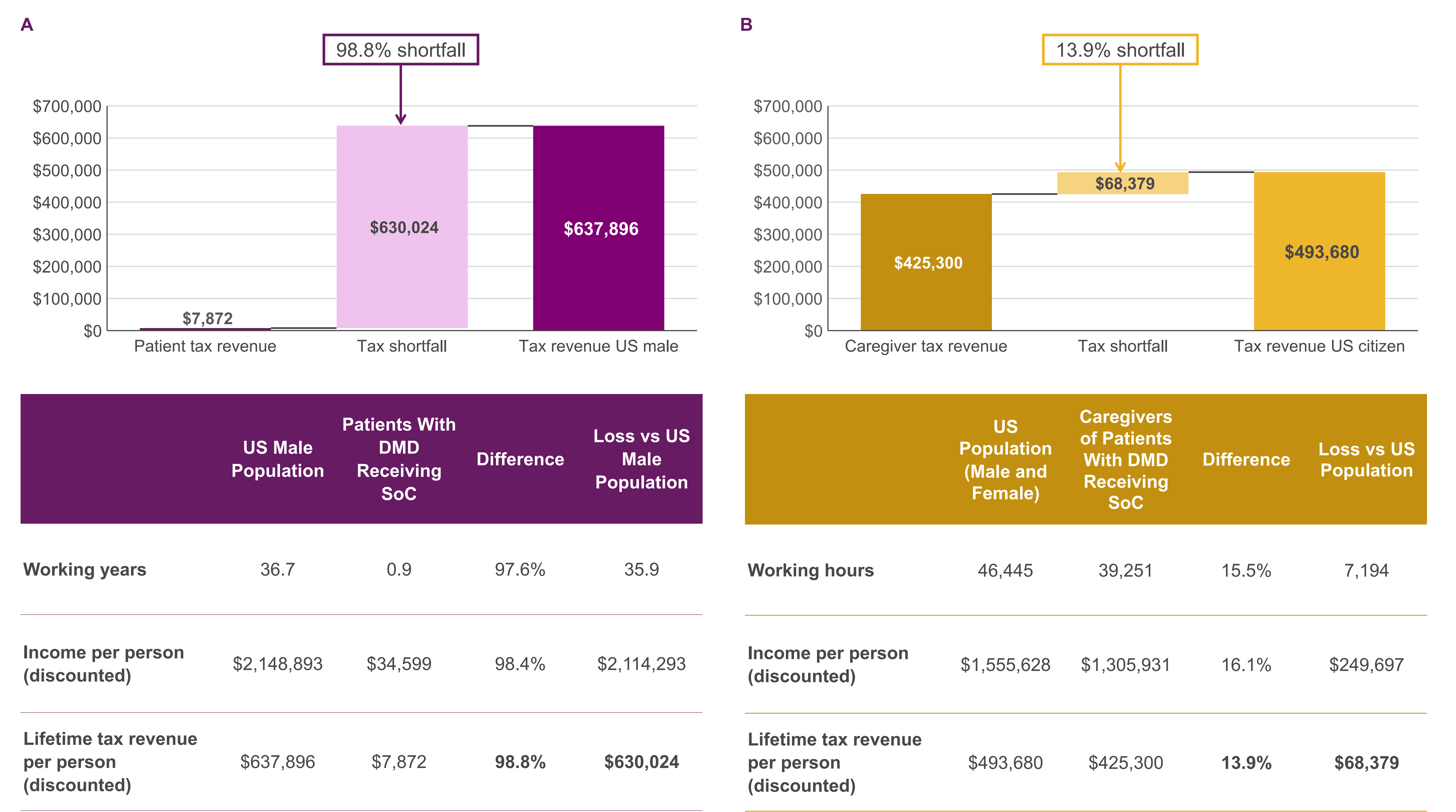
**Figure 2** Partitioned survival model for DMD



## Results

- Patients with DMD receiving SoC work 35.9 fewer years than the US male population, resulting in a lifetime loss of income of \$2,114,293 per patient (**Figure 3A**)
  - That loss of income translates to a lifetime tax shortfall of \$630,024 (98.8%) per patient, with \$7,872 in taxes paid compared with \$637,896 for the average US male
- Caregivers of patients with DMD lose 7,194 working hours and \$249,697 lifetime income compared with the US general population, equating to a lifetime tax shortfall of \$68,379 (13.9%) per caregiver (\$425,300 vs \$493,680) (**Figure 3B**)

**Figure 3** Loss of lifetime tax revenue for patients with DMD receiving SoC (A) and caregivers (age, ≥31 years) of patients with DMD receiving SoC (B)



Conclusions

- This study builds upon a prior analysis that quantifies how DMD negatively impacts the work opportunity for both patients and their caregivers, reducing their time spent in the workforce and their lifetime income
- In the present analysis, patients with DMD faced a near-complete loss of lifetime income compared with the US male patient population, resulting in significant losses in potential tax revenue
- Caregivers also demonstrated a substantial reduction in lifetime income compared with the overall US population—further contributing to tax revenue losses
- The impact of DMD on work opportunities and productivity includes patient, caregiver, and societal considerations

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