# DMD in Germany: A Societal Cost Analysis

EE760

T. Hackmann[1], M. Bill[2], S. Niederberger[2], L. Beilschmidt[1], and D. Voss[1]
[1]Roche Pharma AG, Grenzach-Whylen, Germany
[2]Polynomics AG, Olten, Switzerland

## INTRODUCTION

- Duchenne muscular dystrophy (DMD) is the most common hereditary neuromuscular disease[1]
- With no causal therapy currently available in Germany, DMD causes progressive muscle degeneration from early childhood, leading to severe disability with mobility loss and premature death[1,2]
- This study aimed to determine the societal costs of DMD in Germany in 2022
- Further socioeconomic studies that also assess the potential benefit of novel gene therapies are currently ongoing in Austria and Switzerland

## METHODS

- The average annual costs per person with DMD (pwDMD), lifetime costs for a pwDMD with average disease course, and total societal annual costs for all pwDMD were assessed based on a targeted literature review
- Recent studies providing Germany-specific data by DMD stage (ambulatory/non-ambulatory) were included
- Costs were adjusted to 2022 price levels based on relevant price developments for individual cost components and analysed by DMD stage and cost type (direct: medical/non-medical expenses; indirect: productivity loss/informal care; intangible: loss of quality of life [QoL])

**Table 1: Overview of literature used by cost type**

| Cost type | Source used | Year | Illness stages |
|---|---|---|---|
| Direct costs | Schreiber-Katz et al. (2014)[3] | 2012 | Early/late ambulatory<br>Early/late non-ambulatory<br>Late non-ambulatory with confinement to bed |
| Indirect costs | Schreiber-Katz et al. (2014)[3] | 2012 | See above |
| Intangible costs | Landfeldt et al. (2014)[4] for patients<br>Landfeldt et al. (2016)[5] for caregivers | 2012 | Early/late ambulatory<br>Early/late non-ambulatory |

**Figure 1: Analysed cost types comprising the societal costs associated with DMD**

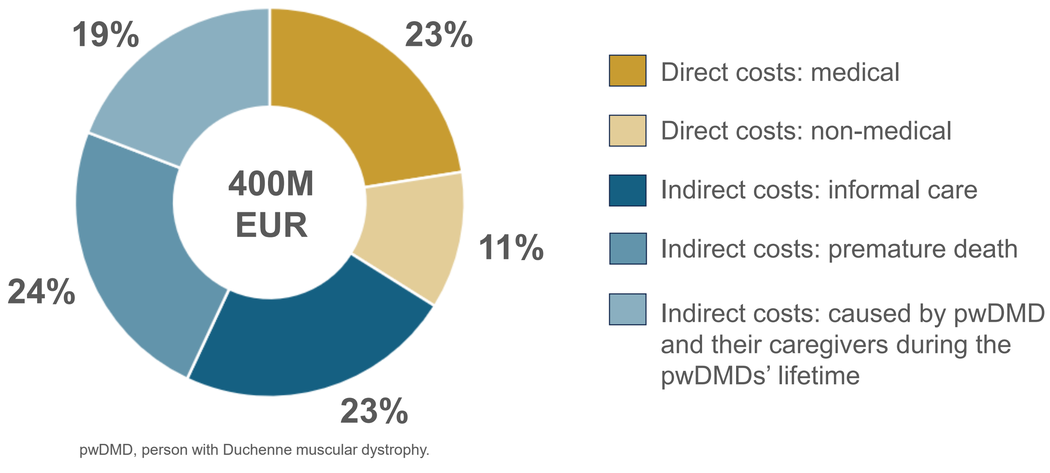
**Direct costs**
Medical and non-medical costs of treatment

**Indirect costs**
Lost resources, especially productivity losses incurred by the pwDMD and their carers

**Intangible costs**
Lost QoL due to pain and suffering

## RESULTS

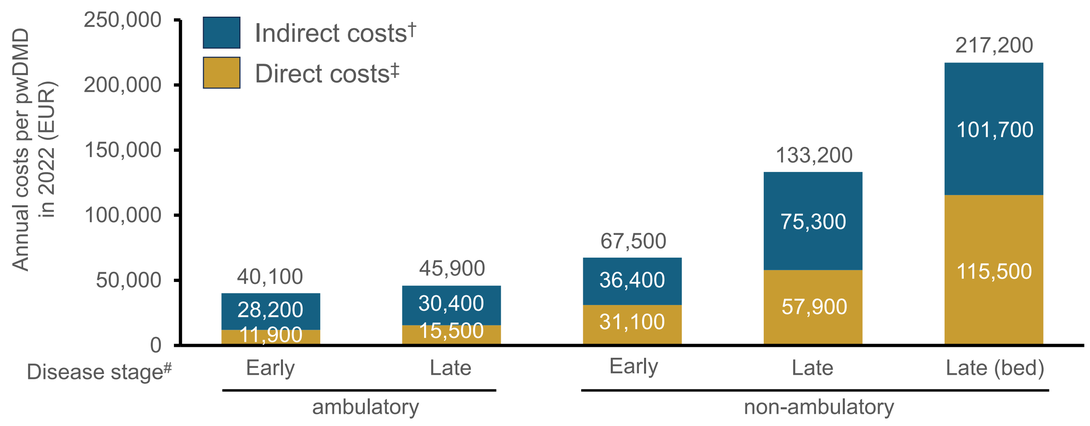
**Figure 2: Total societal annual costs in Germany in 2022**




pwDMD, person with Duchenne muscular dystrophy.

- Total annual societal costs: €400M (95% confidence interval) regarding DMD-prevalence estimate: €280-560M)
- At 66% of the total costs, indirect costs are one of the largest cost drivers due to informal care (provided by family members; 23%), productivity losses (pwDMD & caregivers; 19%), and premature death (24%)
- Total annual costs per pwDMD: €136,500 (€90,200 indirect costs; €46,300 direct costs)

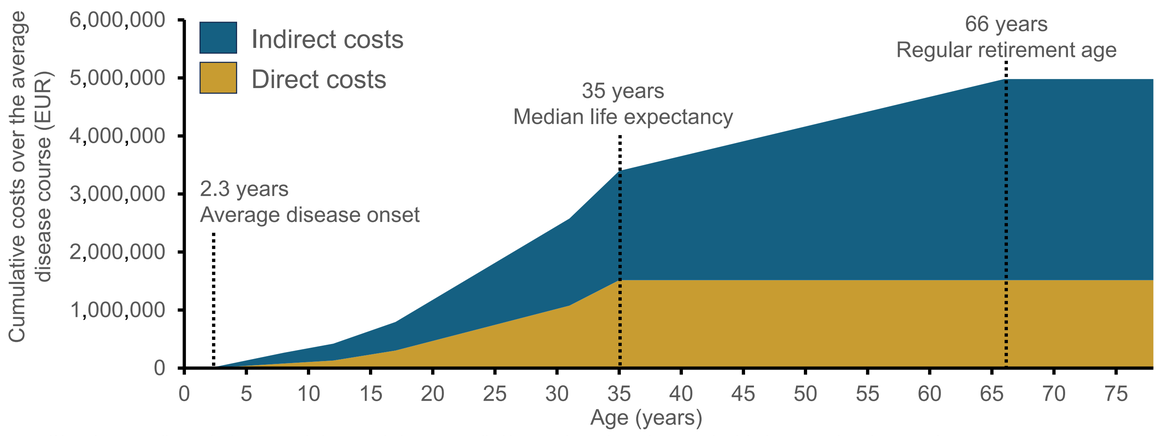
**Figure 3. Annual costs in EUR (for 2022) per pwDMD by disease stage (rounded to the nearest hundred) based on an estimated number of pwDMD***




*The global DMD prevalence rate reported by Crisafulli et al. (2020)[6] – approximately 7.1 cases/100,000 males – was used to infer estimated numbers of pwDMD in Germany for this analysis, amounting to N=2,905 pwDMD. The costs of premature death are not included. †Includes informal care, premature death, and costs caused by pwDMD and caregivers during pwDMD's lifetime. ‡Includes medical and non-medical costs. #Duration per disease stage (years): ambulatory early/late, 6.60/3.40; non-ambulatory early/late/late (bed), 5.55/13.37/3.78. pwDMD, person with Duchenne muscular dystrophy.

- Steep cost increase in late non-ambulatory stages due to longer duration of stay in these stages
  - Ambulatory: €40,100–45,900 per pwDMD per year
  - Non-ambulatory: €67,500–217,200

**Figure 4. Cumulative lifetime costs per pwDMD over the average disease progression**




*Note that according to the human capital approach that was applied here, retirees do not incur productivity losses as they do not work anymore.
pwDMD, persons with Duchenne muscular dystrophy.

- Cumulative lifetime costs for a pwDMD with average disease course were estimated to be €4.98M
- Only around 30% stemmed from direct costs, and approximately 70% from indirect costs
- Costs increased considerably upon entering non-ambulatory stages (ages 12–15) until death
- Nearly half (46%) of the indirect costs were incurred due to patients' productivity losses following their death*

**Table 2. Intangible costs by stage expressed in total QALYs lost by all pwDMD, their caregivers, and per pwDMD over the average disease progression**

| | Ambulatory | | Non-ambulatory | | Death | Total |
|---|---|---|---|---|---|---|
| QALYs | Early | Late | Early | Late | | |
| Intangible costs – QALYs pwDMD | 76 | 60 | 330 | 1,204 | 2,041 | 3,712 |
| Intangible costs – QALYs caregiver | 6 | 9 | 35 | 91 | 0 | 141 |
| Total intangible costs – QALYs | 82 | 69 | 365 | 1,295 | 2,041 | 3,853 |
| **Lost QALYs per pwDMD over disease progression** | **0.9** | **0.8** | **4.1** | **14.6** | **40.0** | **60.4** |

DMD, Duchenne muscular dystrophy; pwDMD, person with DMD; QALY, quality-adjusted life years.

- In 2022, the loss in QoL amounted to 3,853 years for all pwDMD and caregivers
- Over the lifetime of a pwDMD, the loss in QALYs adds up to 60.4 years per pwDMD

## CONCLUSIONS

- DMD imposes a substantial economic burden, with estimated lifetime costs of €4.98M per pwDMD and €400M in total annual costs across all pwDMD (total healthcare expenditures amounted to €497,700M in 2022 in Germany[7])
- Indirect costs account for two-thirds of the total, driven by productivity losses and informal caregiving
- The late non-ambulatory stage contributes most substantially to overall costs
- Intangible costs – such as reduced QoL for pwDMD and their caregivers – are also considerable
- The study highlights the urgent need for novel disease-modifying therapies in DMD with the potential to slow disease progression during early stages, extend life expectancy, improve QoL, and thereby possibly reduce societal costs

## ACKNOWLEDGEMENTS

This study was sponsored by Roche Pharma AG (Grenzach-Wyhlen, Germany). Writing and editorial support was provided by Ashfield MedComms GmbH (Mannheim, Germany), an Inizio company, and funded by Roche Pharma AG, in accordance with Good Publication Practice (GPP) 2022 guidelines (https://www.ismpp.org/gpp-2022).

## REFERENCES

1. Venugopal V, Pavlakis S. Duchenne Muscular Dystrophy. In: StatPearls. Treasure Island (FL): StatPearls Publishing. Copyright © 2025.
2. Broomfield J, et al. Pharmacoecon Open 2024; 8:79-89.
3. Schreiber-Katz O, et al. Orphanet J Rare Dis 2014; 9:210.
4. Landfeldt E, et al. Neurology 2014; 83:529-36.
5. Landfeldt E, et al. Dev Med Child Neurol 2016; 58:508-15.
6. Crisafulli S, et al. Orphanet J Rare Dis 2020; 15:141.
7. Destatis, Statistisches Bundesamt. Press release nr. 167, 25 April 2024.

## DISCLOSURES

TH, LB, and DV are employees of Roche Pharma AG. MB and SN are employees of Polynomics AG (Olten, Switzerland). The analysis was funded by Roche Pharma AG.

Scan the QR code for a copy of this poster

Presented at ISPOR Europe, Glasgow, Scotland, 9–12 November 2025