

The socioeconomic impact of inherited retinal dystrophies (IRDs) in the United States of America (US) in 2019

Methodology

The socioeconomic burden of inherited retinal dystrophies (IRDs) in the United States of America (US) was estimated using cost-of-illness methodology applying a prevalence approach (Larg & Moss, 2011). This approach involves estimating the number of people with IRDs in a base period (2019) and the costs attributable to IRDs in that period. The analysis was based on a targeted literature review and primary data (survey) collection.

Prevalence

Overall, the prevalence of IRDs in the US was estimated to range between 0.056% to 0.133% (lower to upper bound) or between 184,048 to 437,511 prevalent cases in 2019. The highest proportion of the overall prevalence was attributed to rod-cone dystrophy (27.9% for both upper and lower bound estimates or between 51,325 to 122,007 people).

Prevalence of IRDs in the US (n, 2019)

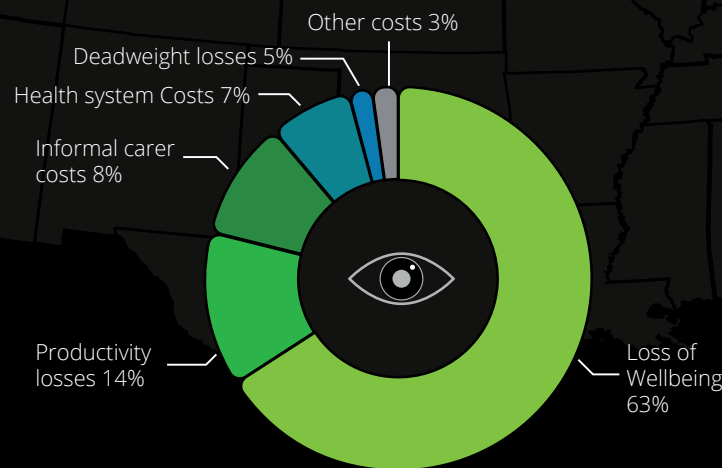
| IRD | Cases (Lower) | Cases (Upper) |
|------------------------|----------------|----------------|
| Rod-cone dystrophy | 51,325 | 122,007 |
| RP | 50,991 | 121,213 |
| Autosomal dominant RP | 15,970 | 37,962 |
| Autosomal recessive RP | 23,534 | 55,945 |
| X-linked RP | 11,487 | 27,306 |
| Stargardt disease | 36,578 | 86,951 |
| Cone-rod dystrophy | 11,436 | 27,185 |
| Choroideremia | 6,573 | 15,625 |
| Best disease | 6,101 | 14,504 |
| Usher syndrome | 5,129 | 12,191 |
| XLRS | 5,070 | 12,051 |
| LCA | 2,895 | 6,881 |
| Cone dystrophy | 2,728 | 6,484 |
| BCM | 1,910 | 4,540 |
| BBS | 1,280 | 3,044 |
| LHON | 1,150 | 2,733 |
| Achromatopsia | 884 | 2,102 |
| Total | 184,048 | 437,511 |

Total costs



Total costs attributable to IRDs in the US were estimated to range between **\$13,414 to \$31,797** million (lower to upper bound) in 2019

Proportion (%) of total costs of IRDs in the US by cost type (2019) (lower and upper bound scenario)



Conclusion

IRDs imposed significant economic and wellbeing costs on the US population in 2019. Persons living with an IRD incur significant economic costs and reductions in their quality of life. Significant economic costs are also borne by families, friends, government, employers and society.

Total costs of IRDs (\$ million, 2019) in the US by condition (lower and upper bound scenario)

