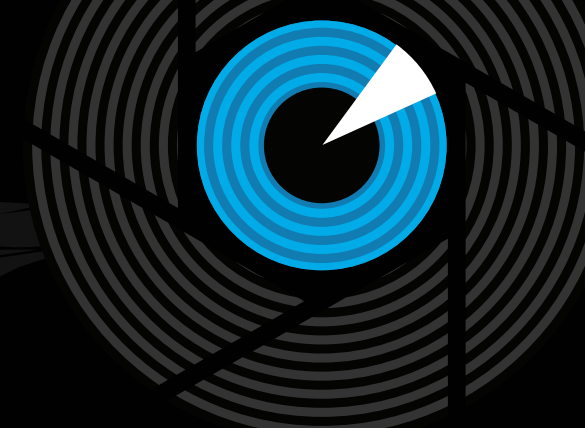


The socioeconomic impact of inherited retinal dystrophies (IRDs) in Canada in 2019



Methodology

The socioeconomic burden of inherited retinal dystrophies (IRDs) in Canada 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 Canada was estimated to range between 0.056% to 0.228% (lower to upper bound) or between 20,947 to 85,672 prevalent cases in 2019. The highest proportion of the overall prevalence was attributed to rod-cone dystrophy (between 27.8% to 27.9% (lower to upper bound) or between 803 to 23,891 people).

Prevalence of IRDs in Canada (n, 2019)

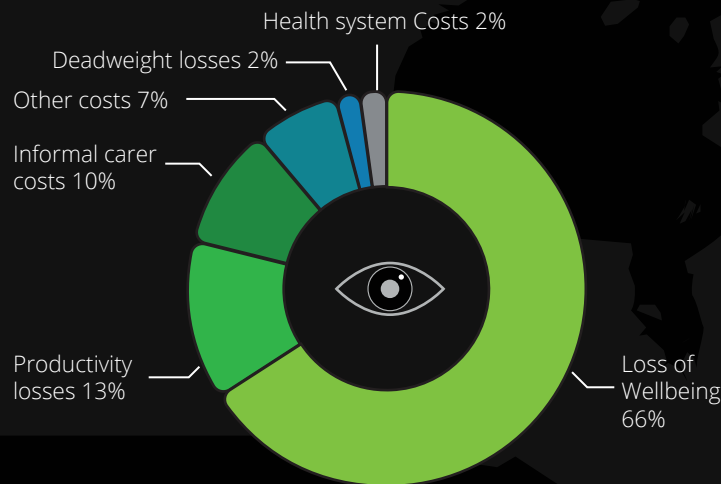
| IRD | Cases (Lower) | Cases (Upper) |
|------------------------|---------------|---------------|
| Rod-cone dystrophy | 5,841 | 23,891 |
| RP | 5,803 | 23,736 |
| Autosomal dominant RP | 1,818 | 7,347 |
| Autosomal recessive RP | 2,679 | 9,607 |
| X-linked RP | 1,307 | 6,782 |
| Stargardt disease | 4,163 | 17,027 |
| Cone-rod dystrophy | 1,302 | 5,323 |
| Choroideremia | 748 | 3,060 |
| Best disease | 694 | 2,840 |
| Usher syndrome | 584 | 2,387 |
| XLRS | 577 | 2,360 |
| LCA | 329 | 1,347 |
| Cone dystrophy | 310 | 1,270 |
| BCM | 217 | 889 |
| BBS | 146 | 596 |
| LHON | 131 | 535 |
| Achromatopsia | 101 | 412 |
| Total | 20,947 | 85,672 |

Total costs

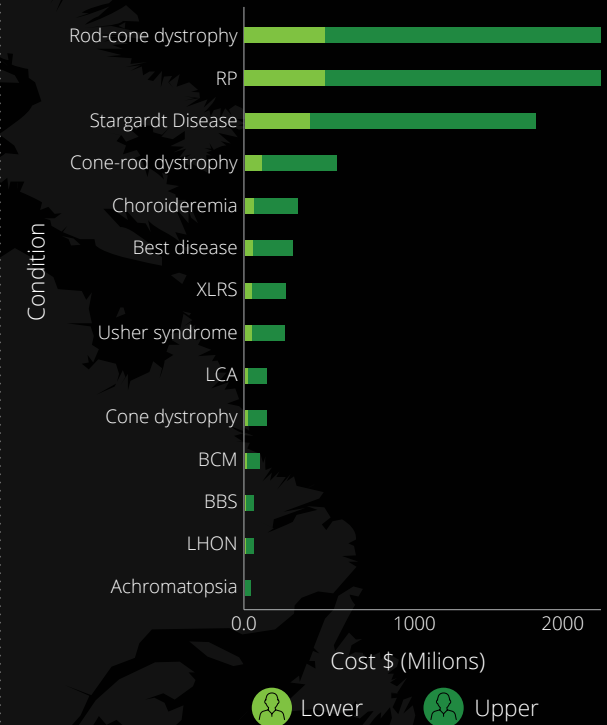


Total costs attributable to IRDs in Canada were estimated to range between **\$1,638 to \$6,688** million in 2019.

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



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



Conclusion

IRDs imposed significant economic and wellbeing costs in the Canadian 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.