

# Socioeconomic impact of Inherited Retinal Diseases; A Cost-of-illness study in the Netherlands

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This study estimates the socioeconomic burden of the 11 most prevalent Inherited Retinal Diseases (IRDs) in the Netherlands in 2023, using a prevalence-based cost-of-illness approach. For resource utilization, a patient survey was used to gather primary data. For prevalence, cost inputs and model localization, a literature review and KOL/PAG inputs were used. Annually, the cumulative financial burden amounts to €155.7 million in 2023. Productivity loss is the main driver at €93.6 million, followed by informal care €27.9 million and direct healthcare costs €25.4 million.

## Introduction

Inherited retinal diseases (IRDs) encompass a range of visually debilitating diseases, leading to significant vision impairment and blindness. Collectively, IRDs are estimated to affect more than 2 million people worldwide with considerable societal impact.<sup>1</sup>

## Objective

Study objective is to measure the socio-economic impact of inherited retinal diseases in the Netherlands.

## Methods

The 11 most prevalent IRD indications were included in this study (Table 3). We employed a prevalence-based cost-of-illness approach to calculate socioeconomic cost associated with IRDs in the Netherlands in 2023. The cost-of-illness framework was tailored to align with Dutch clinical practices and health-economic guidelines<sup>2</sup> (Figure 1 and Table 1).

Figure 1. Overview of cost structure in the study<sup>2,3</sup>

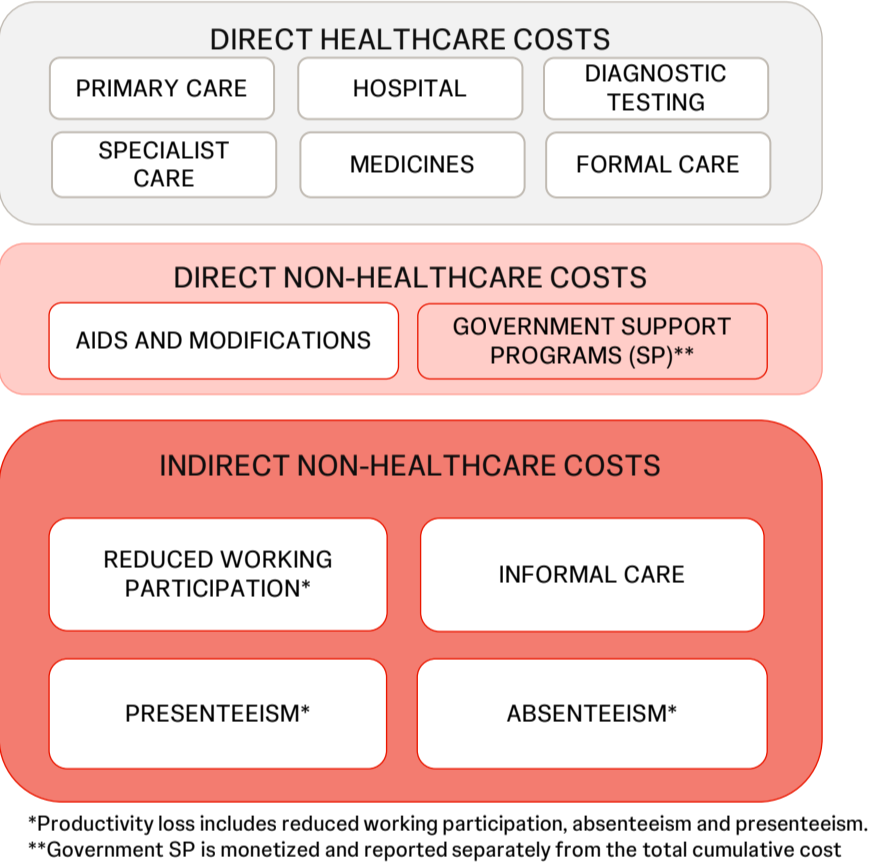


Table 1. Data sources

Component	Data approach
Prevalence	Review of international literature, prioritizing European based prevalence studies.
Direct healthcare costs	Unit costs based on publicly available data and validated by clinical, health-economic and Patient Association experts' input
Direct non-healthcare costs	and Patient Association experts' input
Indirect non-healthcare costs	Informed by patient survey

A literature review was conducted to outline the Dutch patient with IRD pathway, health care service and data sources. The expert panel formed by IRD specialists, genetic counselors and local patient associations were consulted in Step 1 and Step 3, shown in Figure 2.

Figure 2. Col IRDs localization and analysis steps

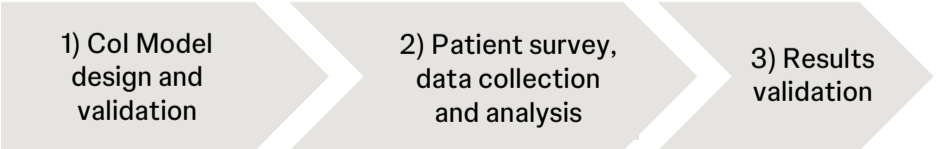
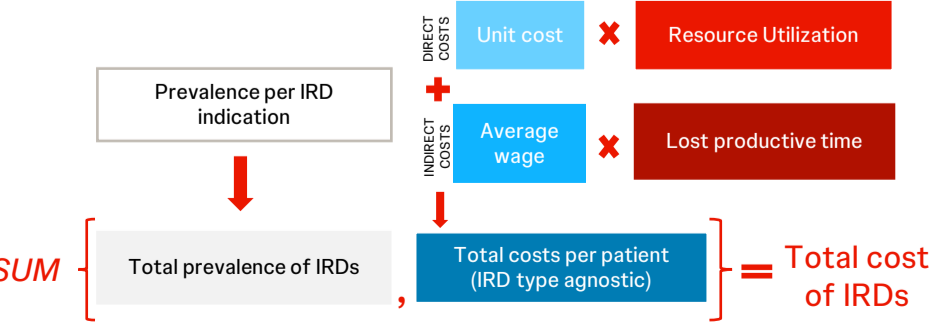


Figure 3. Col Calculation Methodology

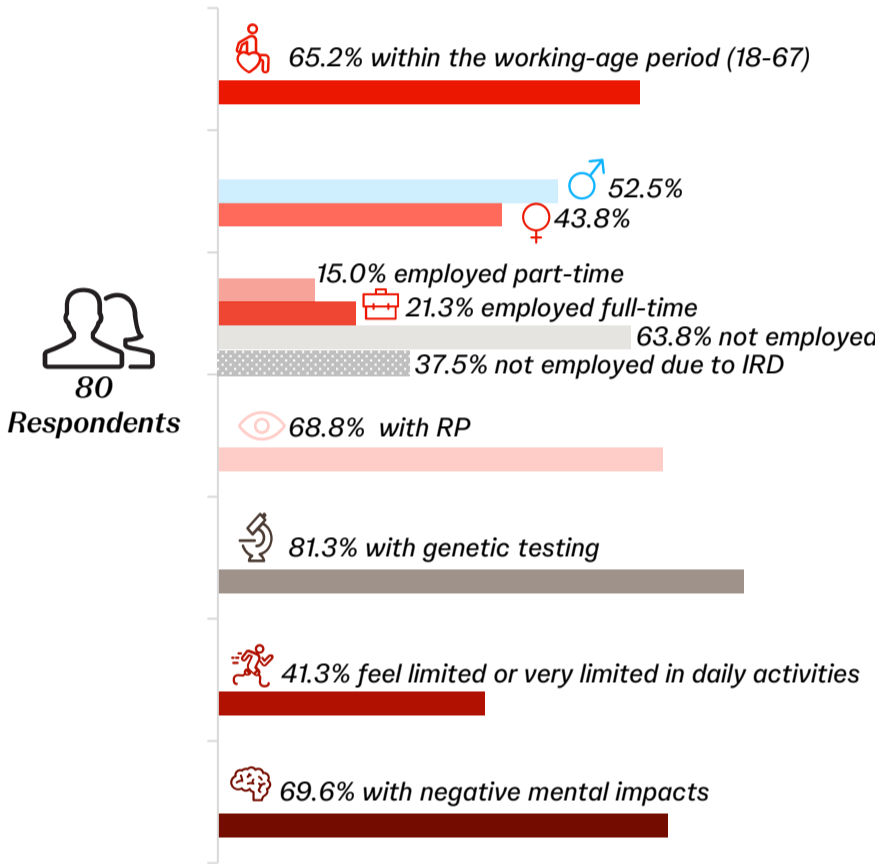


## Results

- ❖ 3 in every 8 survey responders reported being unemployed due to IRD, ~ 9x higher than unemployment rate in the Netherlands<sup>4</sup> (3.5%, 2023)
- ❖ 81% of respondents were genetically tested at baseline
- ❖ 78% of the total cost was attributed to the indirect non-healthcare cost, highlighting IRDs impact on productivity and society

The survey respondent characteristics were similar to the general IRD population characteristics from other countries<sup>5</sup>, in relation to the age, gender and IRD type distribution.

Figure 4. Survey: Patients with IRD baseline characteristics



## COSTS RESULT

Figure 5. Total costs of IRDs (€ millions 2023) in the Netherlands

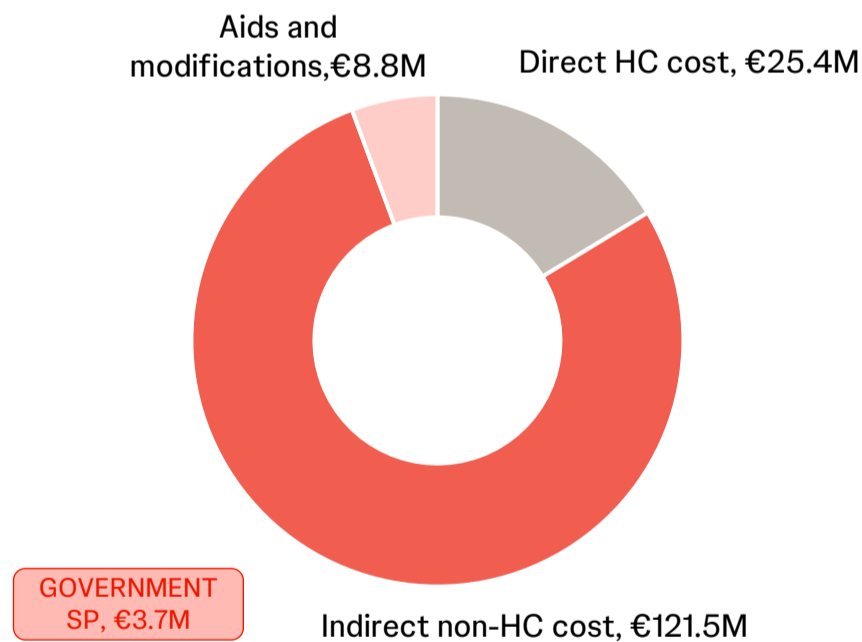


Figure 6. Total indirect non-healthcare costs of IRDs (€ millions 2023) in the Netherlands by cost type

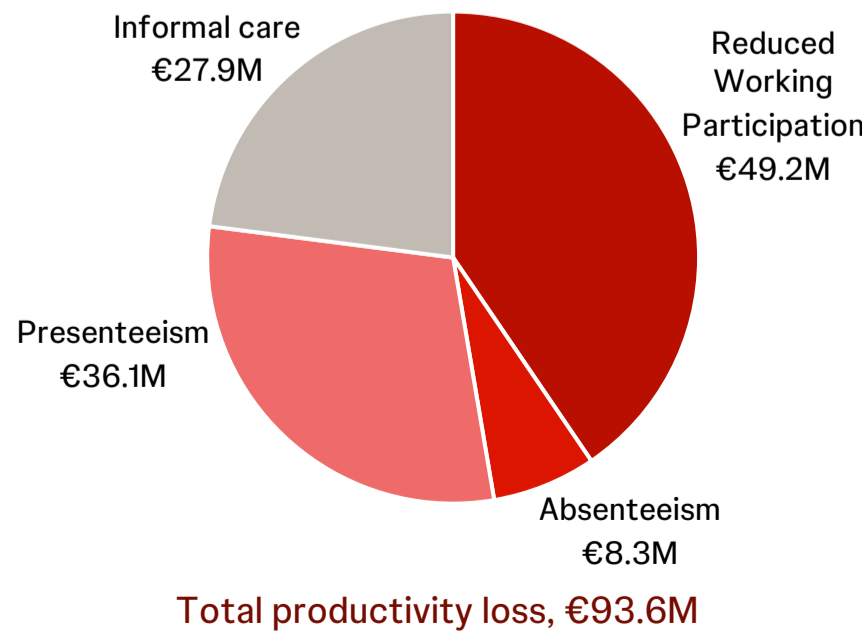


Figure 7. Total direct healthcare costs of IRDs (€ millions 2023) in the Netherlands by cost type

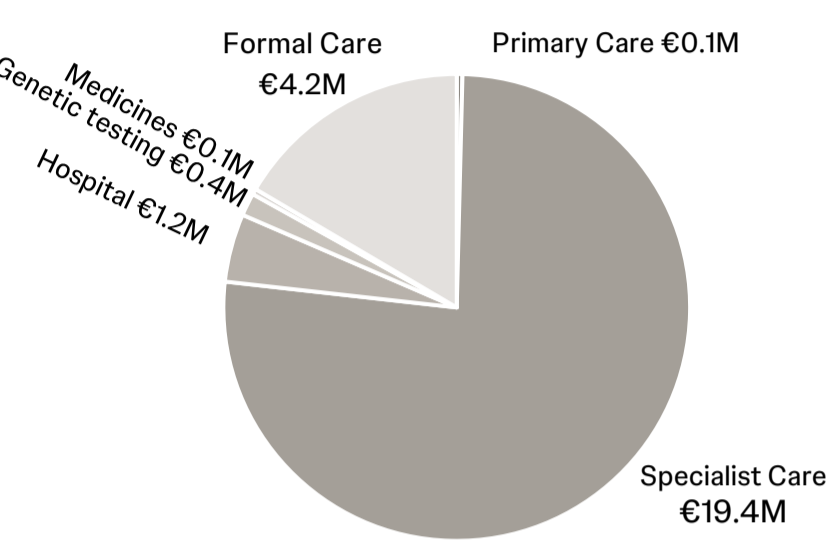


Table 2. Prevalence of IRDs by number of cases & proportion and costs across 11 most common IRDs from survey

	NUMBER OF CASES (CASE PROPORTION %)*	TOTAL COST (€M)
Retinitis Pigmentosa	2,356 (45)	70.7
Stargardt disease	684 (13)	20.5
Usher syndrome	591 (11)	17.7
Congenital stationary night blindness	462 (9)	13.9
Leber congenital amaurosis	362 (7)	10.9
Cone dystrophy	279 (5)	8.4
Cone-rod dystrophy	185 (4)	5.6
Best disease	126 (2)	3.8
Choroideremia	68 (1)	2.0
X-linked retinoschisis	55 (1)	1.7
Achromatopsia	16 (0.3)	0.5

\*Note that the percentages are rounded up from 0,0% format

## Limitations

The study's limitation included the lack of local IRDs' epidemiology and retrospective data collection which may have risks of recalling bias via the patient survey.

## Conclusion

This analysis has found that IRDs impose a significant financial impact on the Dutch economy, with an average annual cost of €30,023 per patient with IRD in 2023 and a cumulative financial burden of €155.7 million in 2023. In addition to the humanistic burden, this study demonstrates a substantial economic burden of IRDs on Dutch society. Therefore, it is important to take into account the considerable societal impact of these conditions in decision-making and policies for the Netherlands, as well as continue to invest in research and development. These future investments can contribute to decrease the financial burden on society, enhance the well-being and productivity of patients with IRD and their relatives.

## References

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