

Global Economic Burden of Retinitis Pigmentosa (RP): A Systematic Literature Review

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CONCLUSIONS

- The SLR underscores the substantial economic burden associated with RP, revealing high healthcare costs across the globe
- The formal care or indirect costs were the major contributor towards the higher cost incurred by the RP population

INTRODUCTION

- Retinal pigmentosa (RP), which includes a class of hereditary retinal dystrophies (IRDs) marked by progressive vision loss, is the primary cause of blindness and visual impairment in people with age < 60 years
- Since there are currently no treatments to cease the progression of the disease or restore vision, RP is regarded as incurable and has a high unmet demand which results to a high illness burden¹

OBJECTIVE

- The systematic literature review (SLR) aims to investigate the global economic burden of Retinitis Pigmentosa (RP)

METHODS

- A systematic search was performed across key biomedical databases (EMBASE[®] and MEDLINE[®]) to identify cost-burden studies conducted in patients with RP published in the last 15-year timeframe (Jan 2009 to May 2024)
- The SLR followed the Preferred Reporting Items for Systematic Reviews and Meta-analyses (PRISMA) guidelines, the Cochrane Handbook, and the National Institute for Health and Care Excellence (NICE) standard approach for conducting this review. The prespecified eligibility criteria is presented in **Figure 1**
- Two independent reviewers reviewed each study, and a third reviewer resolved disagreements

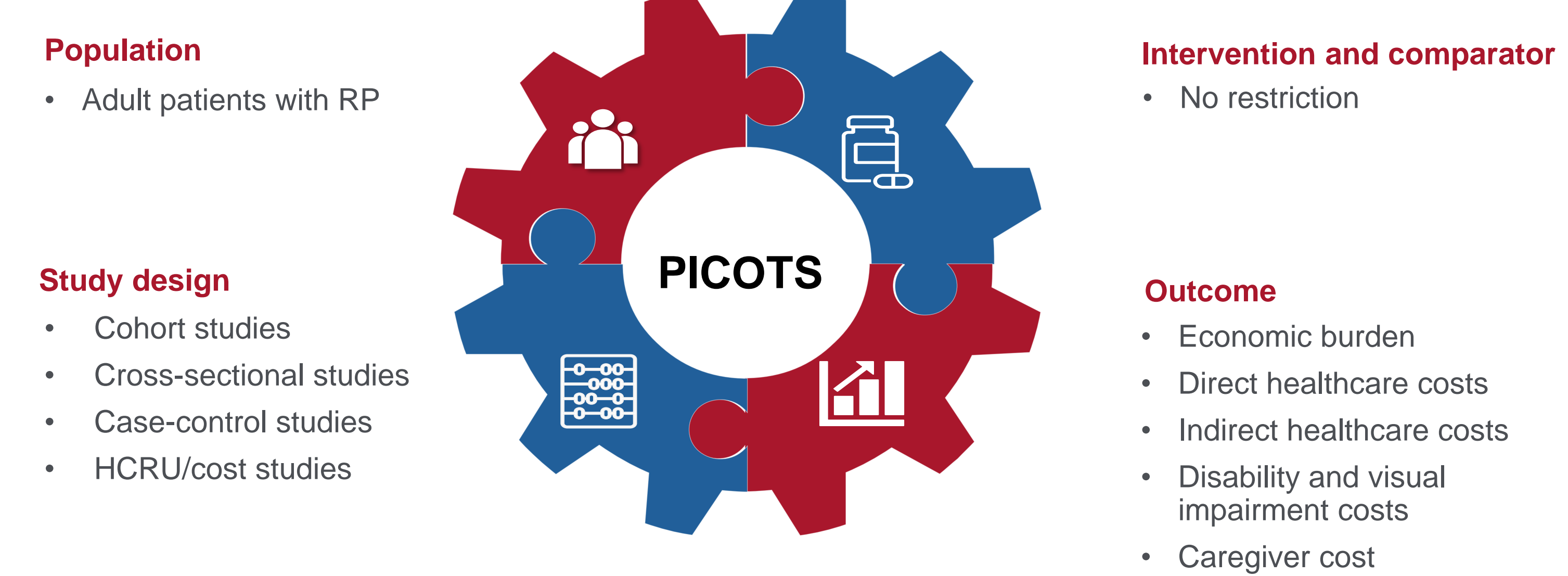


Figure 1: Eligibility criteria for selection of evidence

RESULTS

- A PRISMA diagram for the screening process is presented in **Figure 2**
- Among the 643 publications identified and screened, six studies reported the data for cost burden in patients with RP
- The included studies were conducted in the United States (n=2), Japan (n=2), Spain (n=1) and globally (US and Canada, n=1)

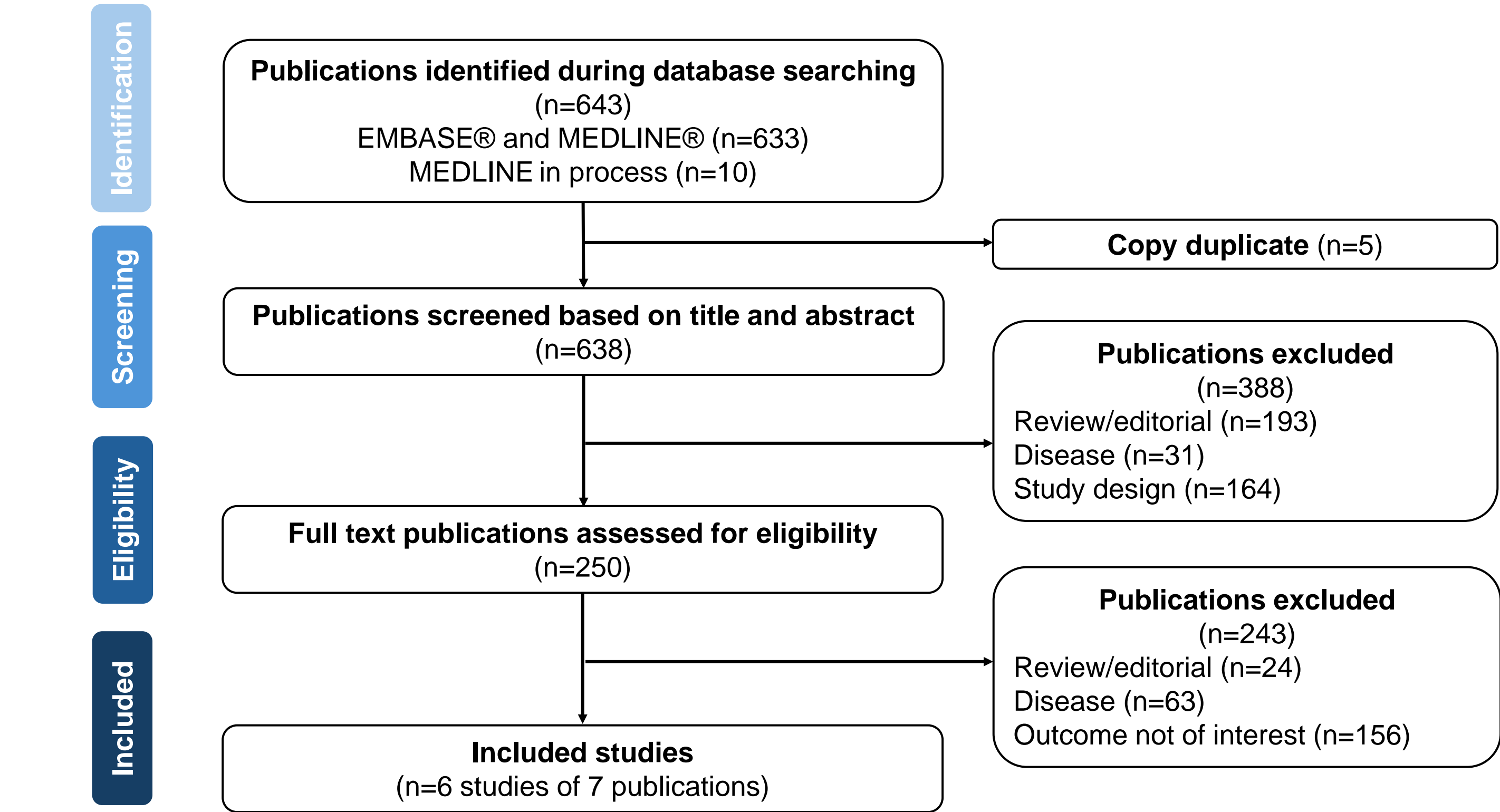


Figure 2: Flow of studies through the systematic literature review

PLAIN LANGUAGE SUMMARY

- A total of six studies reported data for cost burden among patients with RP
- In the US, the estimated total annual cost among prevalent RP patients ranged from US\$ 3,708.4 to US\$ 8,790.6 million. Further, in Canada, the estimated total annual cost among RP patients ranged from CAN\$ 452.5 to CAN\$ 1,847.5 million
- In Japan, the total annual mean cost among RP patients was ¥ 218,520, with a lifetime mean cost of ¥ 18,523,909. In Spain, the mean annual cost for low-vision aids/adaptations among RP patients with visual impairment or blindness was €16,056.5

Table 1: Study characteristics of included studies

Study name	Country	Study design	Publication type	Sample size	Data source
Ferro 2024	USA	Prospective cohort study	Conference Abstract	--	--
Frick 2012	USA	Cross-sectional	Journal Article	2990	MarketScan Commercial and Medicare Supplemental Databases
Gong 2021	USA; Canada	Prospective cohort study	Journal Article	838	Targeted literature review and primary data (survey) collection
Yamanaka 2023	Japan	Prospective cohort study	Conference Abstract	118	--
Watanabe 2023	Japan	Cross-sectional	Journal Article	122	Web-based or telephone surveys
Blanch 2023	Spain	Cross-sectional	Conference Abstract	41	Telephone surveys

- In the US (), the estimated total annual costs among prevalent RP patients ranged from US\$ 3,708.4 to US\$ 8,790.6 million. The largest economic burden comes from the loss of wellbeing, which accounts for 63-65% of the total costs showing how much the condition affects people's quality of life
- The RP patients had significantly higher mean annual total direct healthcare costs than non-RP groups (US\$ 14,988 vs. US\$ 9,965, p<0.001), driven primarily by outpatient costs (US\$ 10,589 vs. US\$ 6,791) (**Figure 3**). Disability and visual impairment among RP patients was associated with higher total lifetime mean costs compared to those without disability (US\$ 2,314,495 vs. US\$ 584,800)

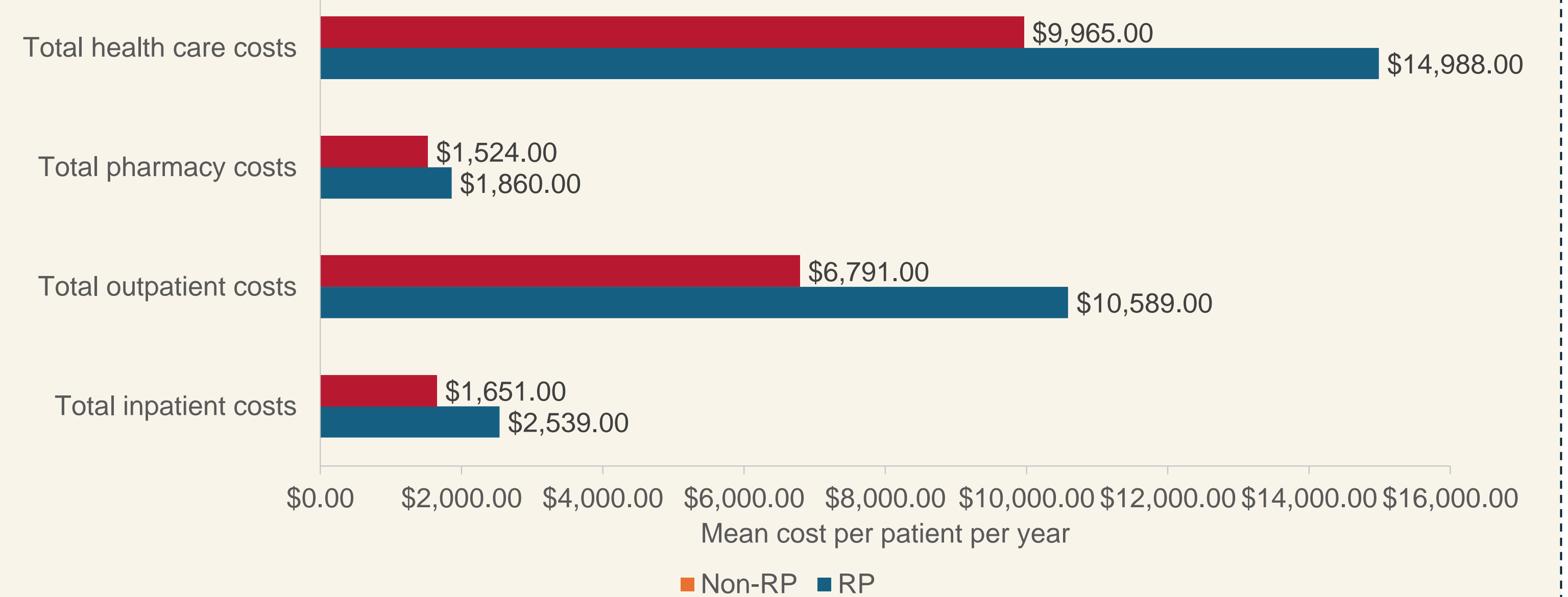


Figure 3: Annual health services cost in United States

- Further, in Canada (), the estimated total annual costs for RP patients ranged from CAN\$ 452.5 to CAN\$ 1,847.5 million
- In Japan (), the total annual mean cost for RP patients was ¥ 218,520, with a lifetime mean cost of ¥ 18,523,909. Formal care (healthcare services and paid care) was the major contributor to annual costs (¥ 191,666, 87%)
- The salary gap (¥ -49,054) is a persistent financial burden, reflecting a long-term reduction in income for patients. Paid care costs (¥ 170,742 on average) can far exceed the salary gap, especially for those needing long-term or specialized care
- The mean annual total societal cost for RP patients was ¥ 1,579,864, with indirect costs (productivity loss and caregiver costs) comprising 68.2%, nearly double the direct costs (**Figure 4**)

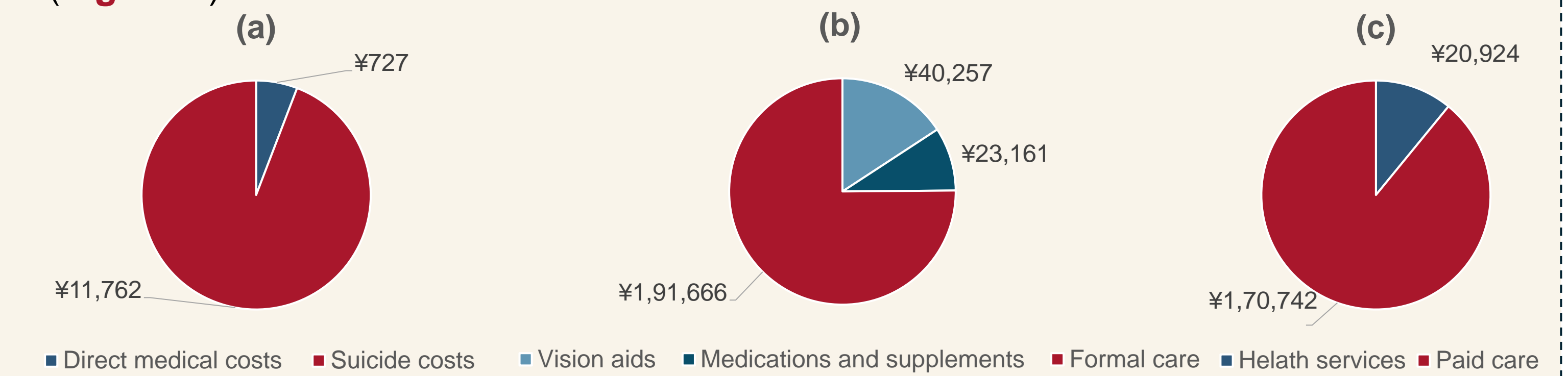


Figure 4: Mean per patient per year cost of (a) depression/anxiety; (b) out of pocket; (c) formal care

- In Spain (), the mean annual cost for low-vision aids/adaptations among RP patients with VI or blindness was €16,056.5, primarily related to optical aids, with caregivers incurring an annual mean indirect cost of €1,040.9

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Disclosures

SK, SA, PR, GK and BS, the authors, declare that they have no conflict of interest