

# The Visible and Hidden Costs of Rare Disease: Learnings from the CORD Canadian Survey

Rare Disease Day Webinar | February 27, 2026

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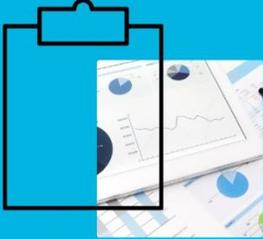
# Acknowledgements



Canadian Organization  
for Rare Disorders

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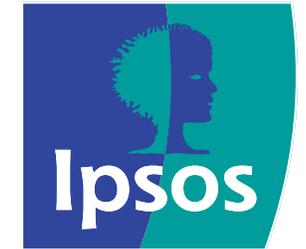
**CANADIAN SURVEY ON  
THE IMPACT OF DISEASE**



**Help Shape Rare Disease Policy in Canada  
Your Voice Drives Change**

**Survey Deadline: June 22**

Survey is available in English and French



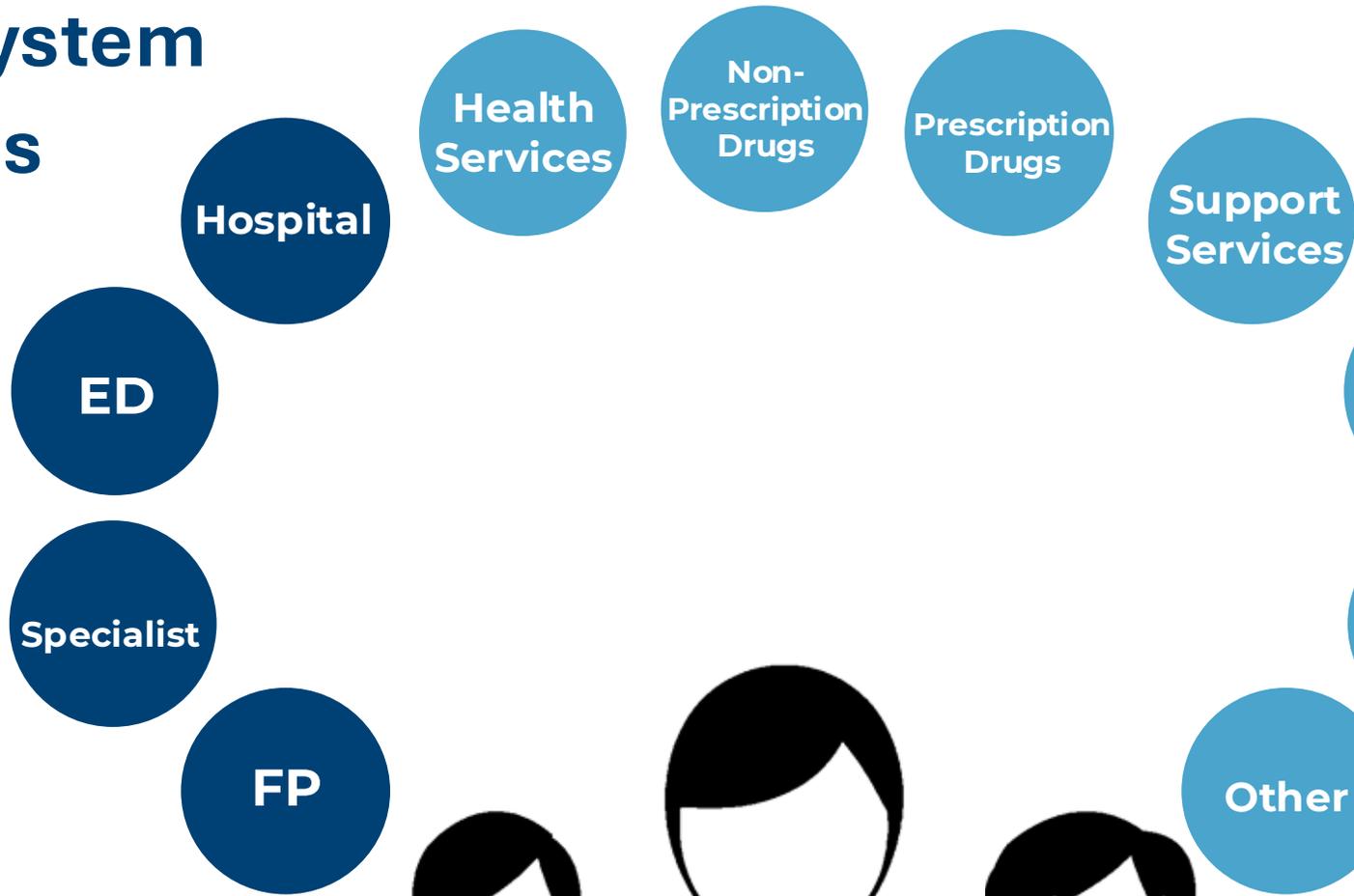
# Methodology

*Ipsos is pleased to have collaborated with the Canadian Organization for Rare Disorders in undertaking these important surveys.*

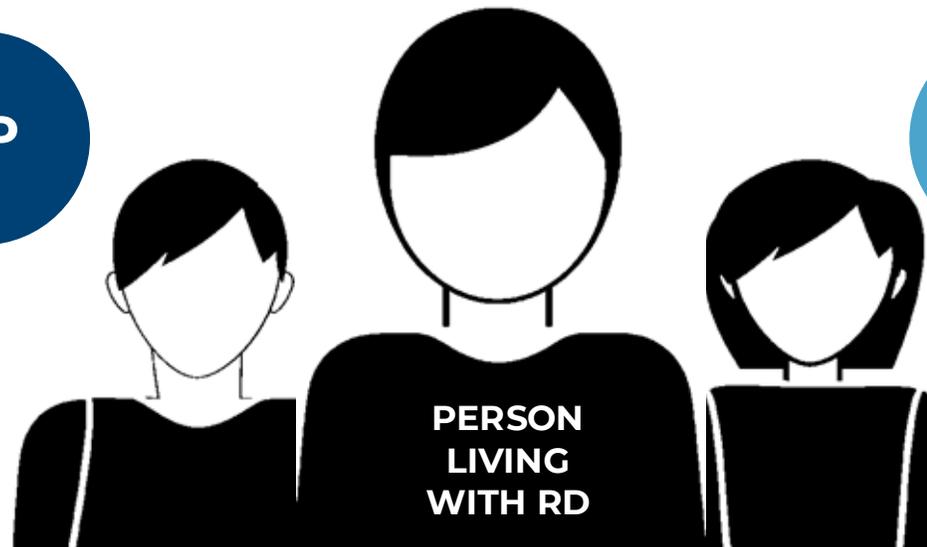
*These surveys provide valuable insights to understand the experiences of individuals living with rare diseases as well as the general Canadian population.*

	Survey of <b>Canadians living with rare diseases (and caregivers)</b>	Survey of <b>Canadians (general population)</b>
<b>Completed surveys</b>	<b>205</b>	<b>1,000</b>
<b>Methodology</b>	Online	Online
<b>Sample source</b>	Provided through CORD membership partners	Ipsos iSay panel
<b>Field dates</b>	April 28 – June 28, 2025	October 24 – 28, 2025
<b>Weighting</b>	None	Age, Gender and Region
<b>Credibility interval</b>	Not calculated as parameters not known	± 3.8 percentage points

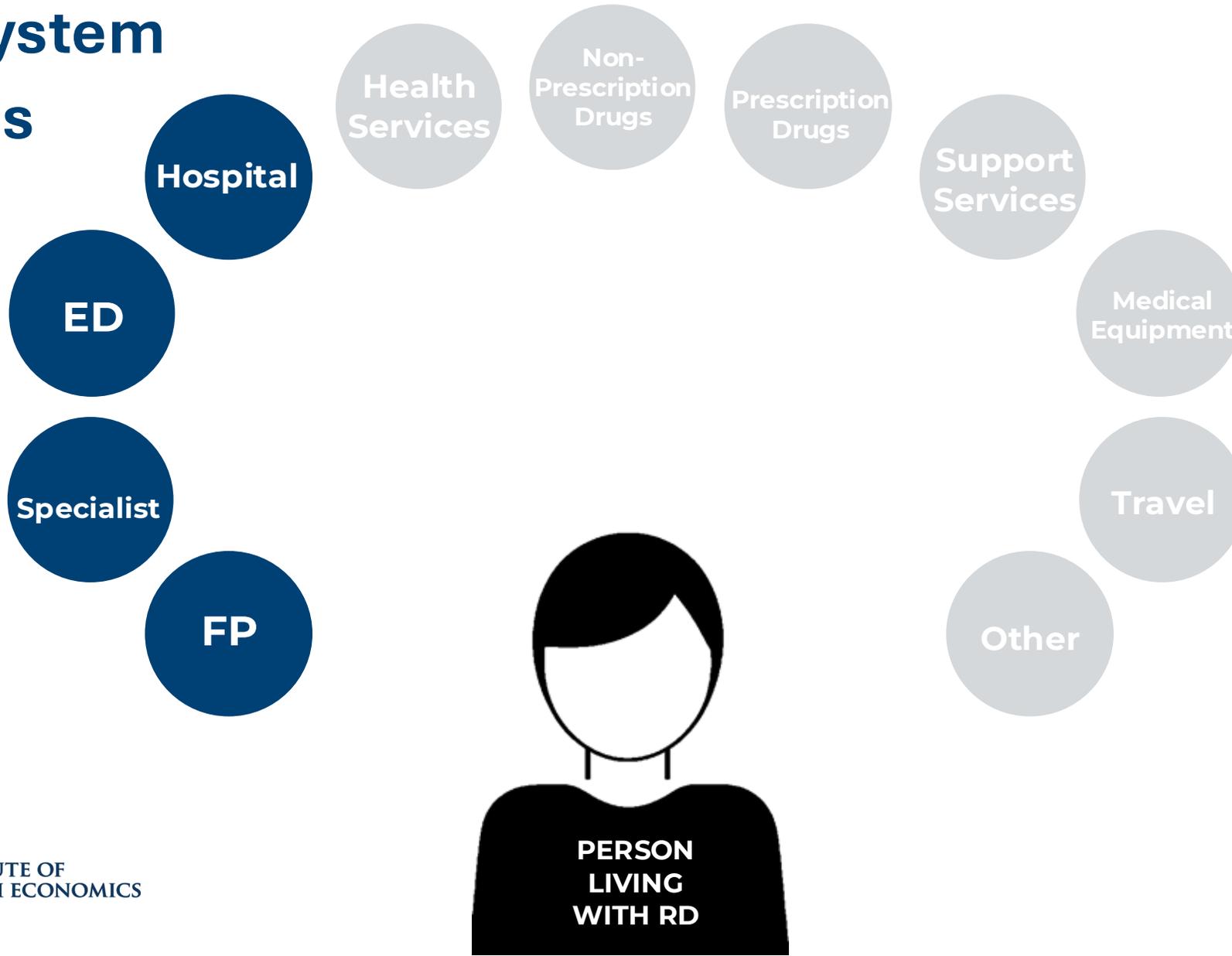
# Visible Health System Costs



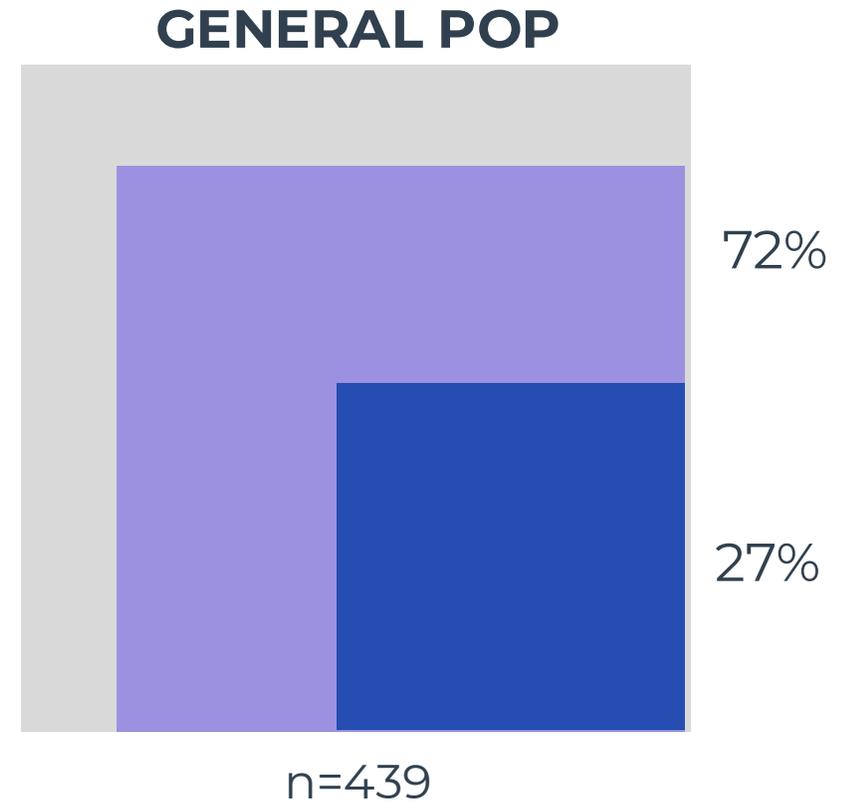
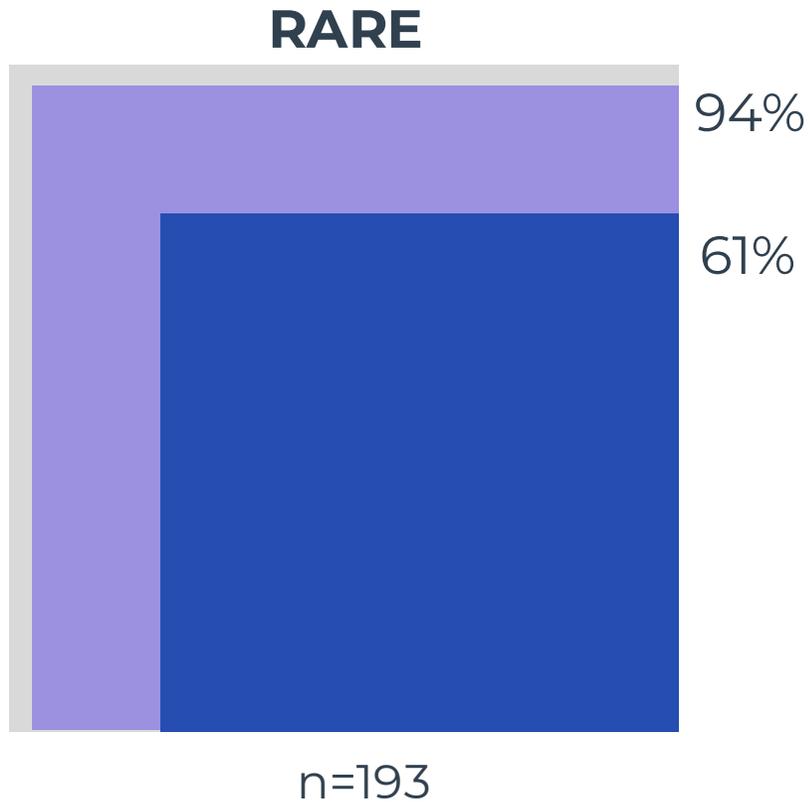
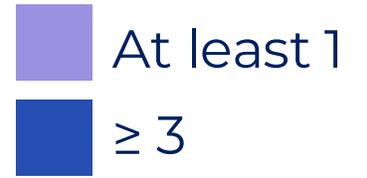
# Hidden Out-of-Pocket Costs



# Visible Health System Costs



# Family Physician Visits



**2x** the average annual cost

\$267 vs \$128

# Rare Disease Drives Higher System Costs Across Care Continuum

Specialists



**7x**  
average  
annual cost

\$497 vs \$70

ED Visits



**4x**  
average  
annual cost

\$440 vs \$113

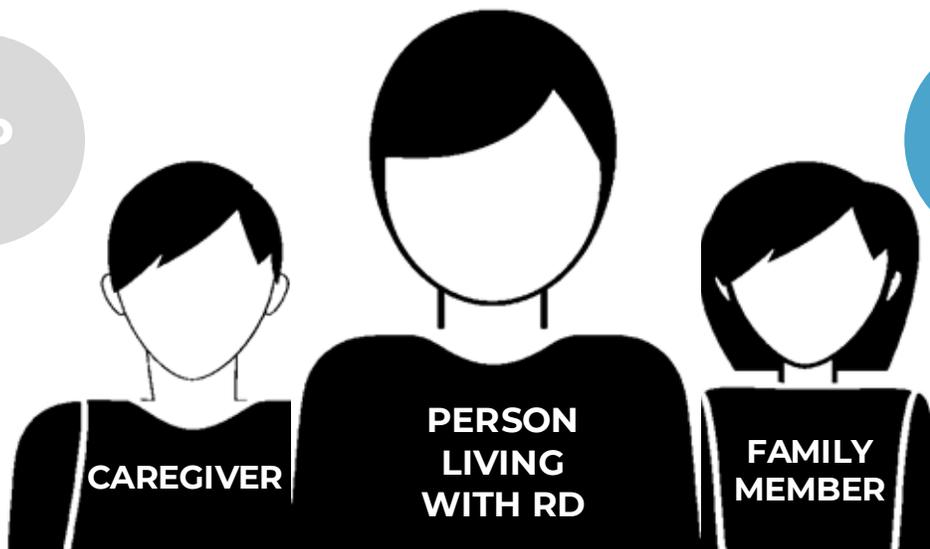
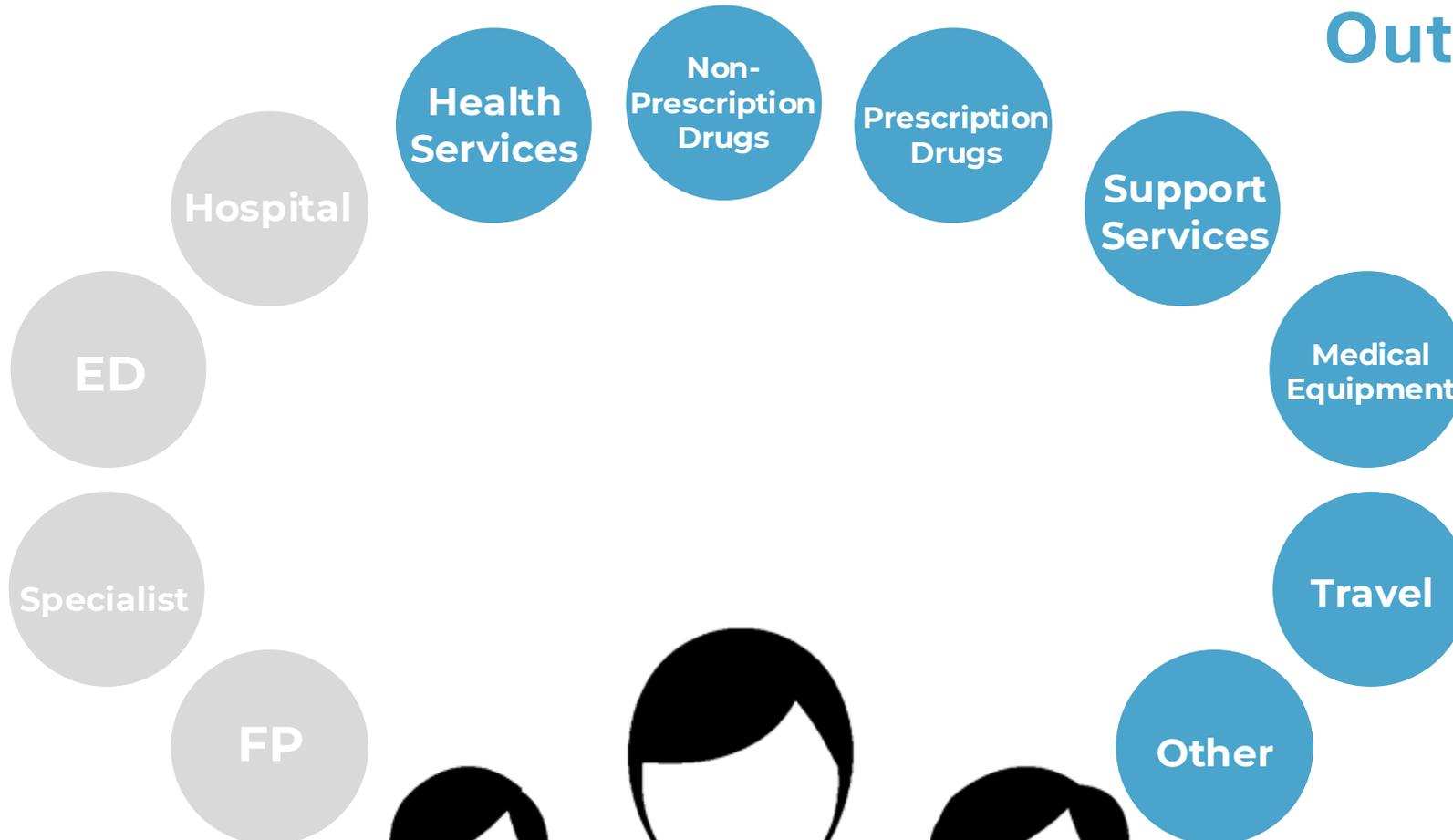
Hospitalizations



**2x**  
average  
annual cost

\$5,243 vs \$2,549

# Hidden Out-of-Pocket Costs



**73% of respondents reported  
paying out-of-pocket for expenses  
related to their care**

(n=205 living with rare disease & caregivers)

# Out-of-Pocket Expenses Related to Care

Expense Type	Maximum Annual	Average Annual
Health Services	\$15,000	\$1,118
Non-prescription Drugs	\$5,000	\$399
<b>Prescription Drugs</b>	<b>\$20,000</b>	<b>\$1,200</b>
Support Services	\$40,000	\$1,168
Medical Equipment	\$22,000	\$771
Other	\$30,000	\$1,472
		<b>\$6,128</b>



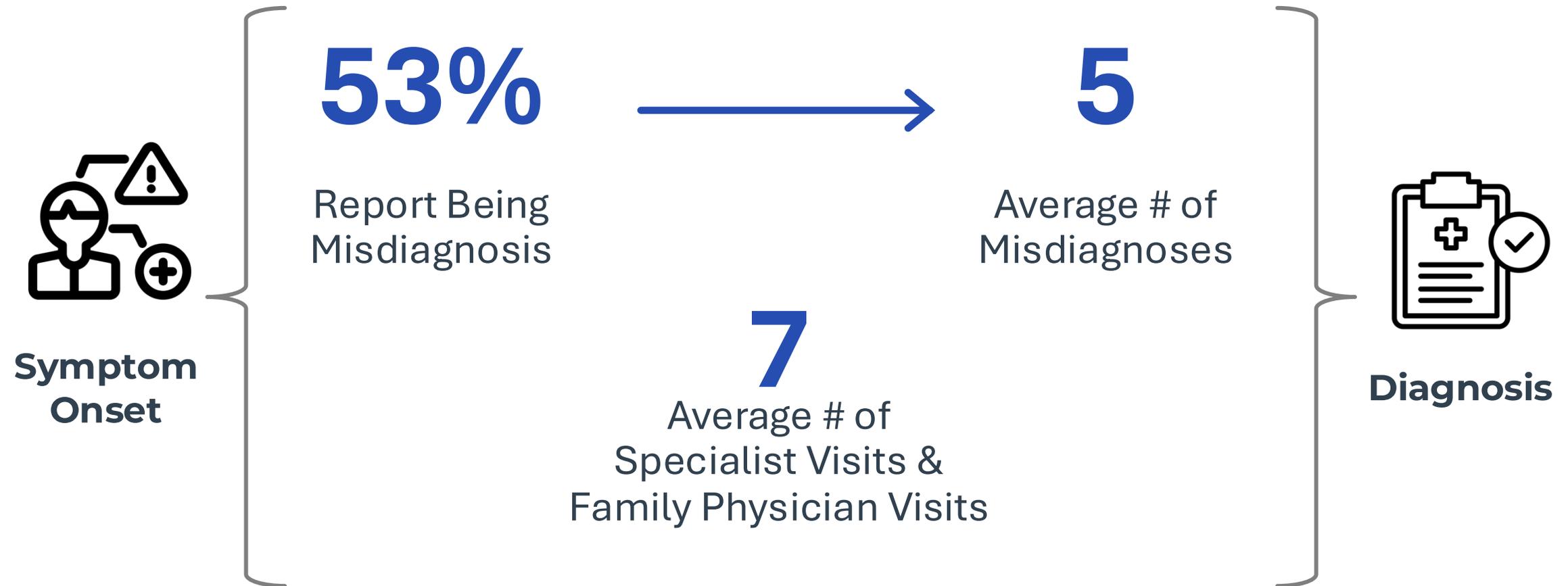
10X  
Gen  
Pop  
Value

“After many years of getting diagnoses for the symptoms of [my child’s] disorder, we finally got a proper answer to the reason behind all of them.

The impact of this [...] rare disease on our family is enormous on all levels: our [child’s] health and quality of life, our physical and mental health, our finances, our social lives and more.”

- Quote from Caregiver Respondent

# Many Experience Multiple Visits & Misdiagnoses



A diagnostic delay of **5+ years** was associated with **1.5x higher out-of-pocket costs** for care

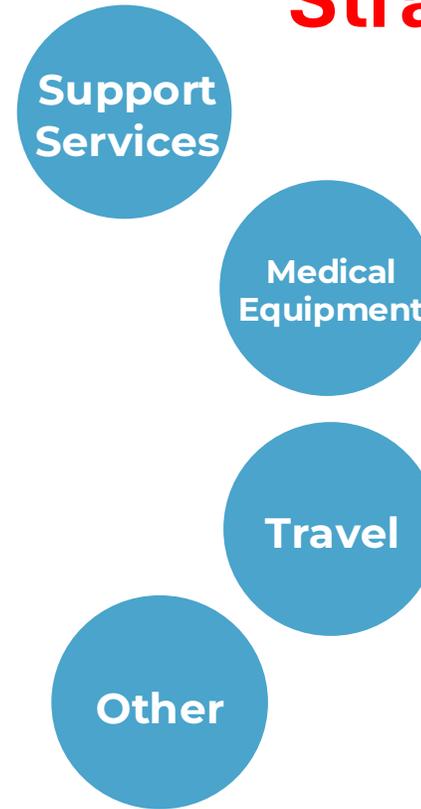
\$6,088 vs \$4,171

(n=54 living with rare disease & caregivers)

# Visible Costs Strain Systems



# Hidden Costs Strain Families



**Diagnostic Delays  
Intensify Costs  
for All**





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