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# Listening To The Voice Of The Patient: Insights From A Survey On The Burden Of Recurrent Respiratory Papillomatosis In The United States

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## INTRODUCTION

- Recurrent respiratory papillomatosis (RRP) is a rare, chronic disease characterized by recurring benign papillomas in the respiratory tract caused by human papillomavirus types 6 and 11; the papillomas lead to airway obstruction, causing significant morbidity and potential mortality.<sup>1-4</sup>
- Repeated surgical procedures are needed to manage RRP.<sup>5</sup>
- On average, adult patients with RRP undergo 13.5 surgeries over their lifetime, though 9% have undergone ≥100 surgeries<sup>1</sup>; recurrence is common, making RRP a lifelong, debilitating condition with no known cure.<sup>1, 2; 6-8</sup>
- Patients have reported a substantial burden associated with constant interruptions to daily life caused by repeated surgeries, affecting quality of life (QoL) and the ability to work.<sup>1, 5; 9</sup>
- Prior research has shown the economic and humanistic burden of RRP; many patients travel long distances for care, missing workdays, and spending a substantial portion of their annual income on treatment, all contributing to reduced work productivity and QoL.<sup>10</sup>
- Critical gaps remain in understanding the lived experience of adult patients with RRP, particularly those with high surgical burden.


## OBJECTIVE

- To characterize the impact of RRP on the patient journey and QoL of adult patients in the United States (US).

## METHODS

- A 60-minute electronic survey was conducted in June 2025 among adults with RRP in the US.
- The survey collected data on demographics, surgical burden, treatment history, medication use, socioeconomic impact, tracheotomy rates, quality of life, level of debilitation, impact on daily life and caregiving, and physical and mental health effects of RRP.
- The study protocol was reviewed and determined to be exempt by an institutional review board.
- Survey responses were analyzed descriptively; frequencies and percentages were reported for categorical variables.
- A subgroup analysis was conducted to characterize patients with high surgical burden (≥3 surgeries in the year prior). Exclusion criteria were as follows:
  - Less than 18 years of age; currently enrolled in an investigational drug trial or device study for the treatment of RRP; and unable or unwilling to participate in a 60-minute survey conducted in English.

## RESULTS

- **Baseline Characteristics:**
  - 52 adults with RRP (65% male) completed the survey; mean age was 32.6 years.
  - Mean age at diagnosis was 29.5 years.
  - Respondents were living with RRP for 2-5 years.
  - The median surgeries in the past year was 1; 31% of patients underwent ≥3 surgeries in the year prior (i.e., high surgical burden); 44% had 1-2 surgeries and 25% had none.
  - 90% were employed or self-employed.


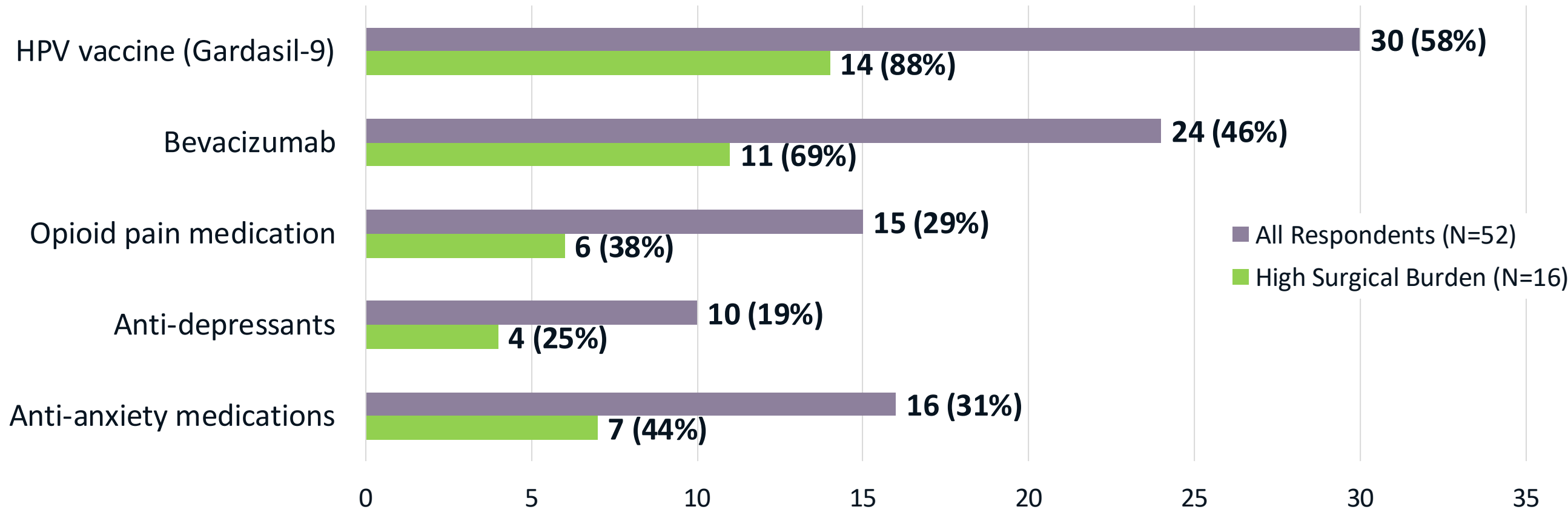
- **Treatment History and Medication Use (Figure 1):**
  - Prior Gardasil and bevacizumab use in 58% and 46% of patients was respectively reported in the overall group, rising to 88% and 69% of patients with high surgical burden.
  - Overall, 29% of patients used opioids and 50% of patients used antidepressants/anti-anxiety drugs, increasing to 38% and 69% in patients with high surgical burden.

Figure 1. Treatment history and medication use in the past year among all respondents (N=52) and respondents with high surgical burden (N=16)




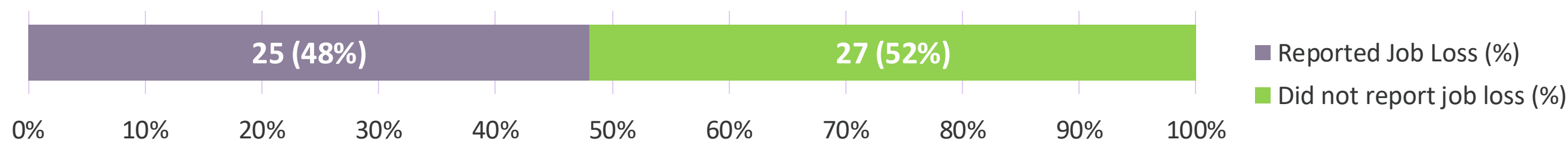
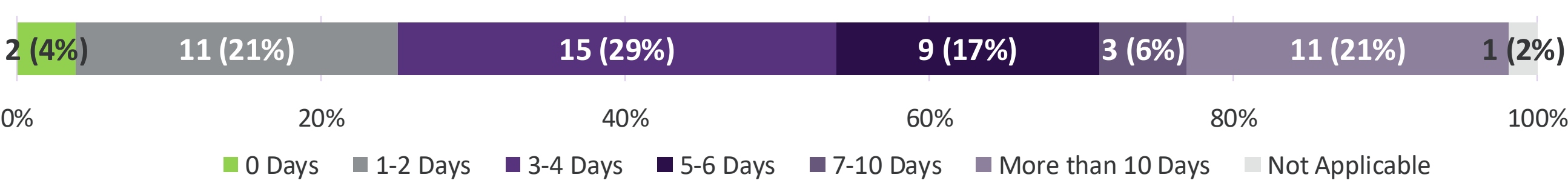
- **Socioeconomic Burden:**
  - Job Security (Figure 2):**
    - Roughly 50% of patients sampled have lost a job in the past due to RRP.

Figure 2. Job loss due to RRP (N=52)



- Productivity Loss (Figure 3):**
  - 44% of patients missed ≥5 workdays per month.
  - 75% of patients reported missing 3 or more working days per month.

Figure 3. Missed workdays due to RRP (N=52)




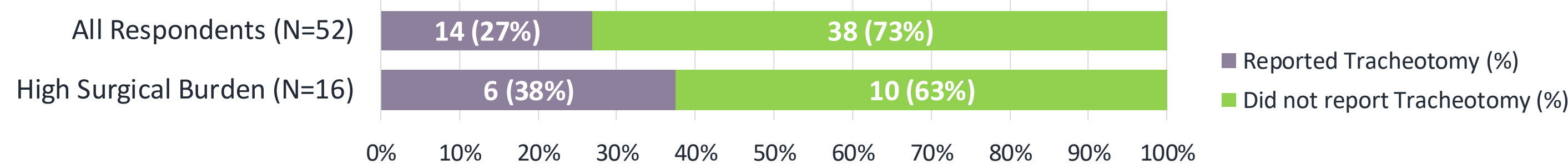
- **Frequency of Tracheotomy (Figure 4):**
  - Tracheotomy was reported by 27% of patients, increasing to 38% in patients with high surgical burden.

Figure 4. Tracheotomy procedures among all respondents (N=52) and respondents with high surgical burden (N=16)




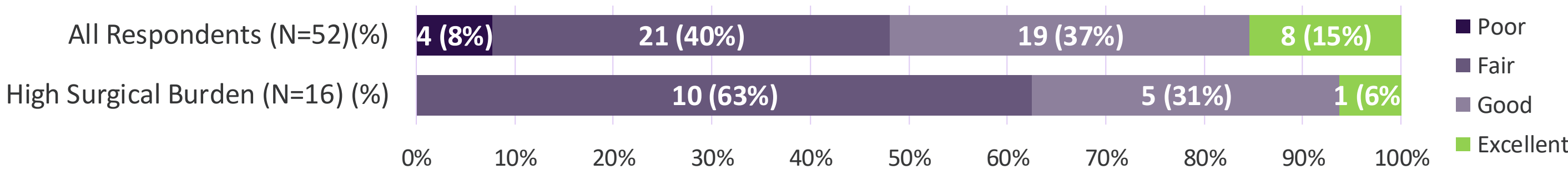
- **QoL (Figure 5):**
  - Post-diagnosis QoL was rated as fair or poor by 48% of patients, increasing to 63% in patients with high surgical burden.

Figure 5. Impact of RRP diagnosis on QoL among all respondents (N=52) and respondents with high surgical burden (N=16)




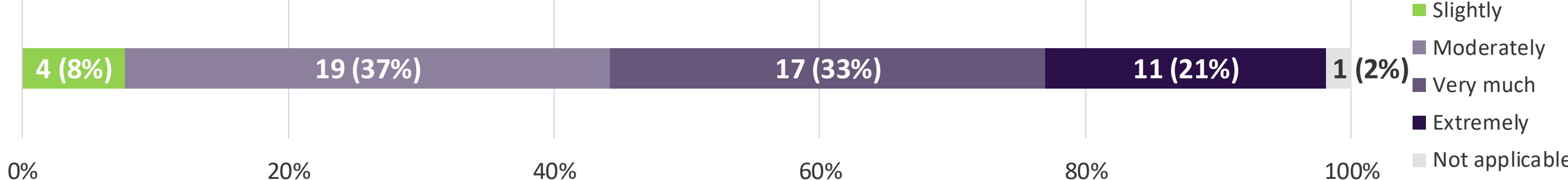

- **Level of debilitation (Figure 6):**
  - 90% of patients found RRP moderately to extremely debilitating.
  - 54% of patients felt very or extremely debilitated by RRP.

Figure 6. Level of debilitation due to RRP (N=52)



- **Impact of RRP on daily life and care**
  - 90% of RRP caregivers missed more than 1 day of work per month.
  - ~70% of patients reported that RRP had a moderate to extreme impact on family planning.
  - Roughly three quarters of patients surveyed see their doctor for RRP-related care 1-3 times per month.


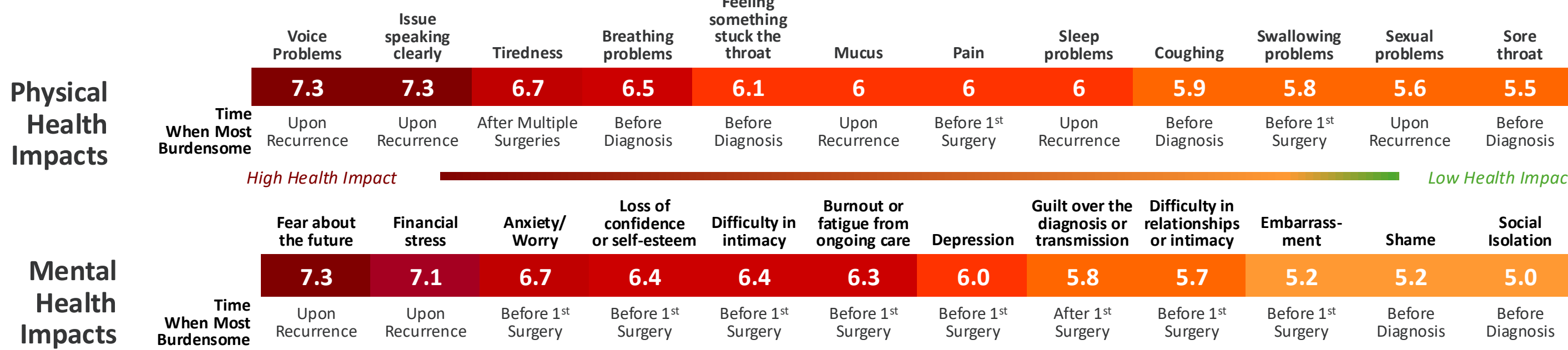
- **Physical and Mental Health Impacts from RRP (Figure 7):**
  - Voice problems and issues speaking clearly were the physical health measures with the highest impact on patient health, while fear about the future and financial stress were the mental health factors with the highest health impact; those impacts are the most burdensome upon recurrence.

Figure 7. Top physical and mental health impacts on patients from RRP (N=52)



## DISCUSSION & CONCLUSIONS

- The results from this survey provided rich insights into the lived experience of adults with RRP in the US.
  - Despite prior treatment with Gardasil and bevacizumab, disease burden remained high, indicating unmet therapeutic needs.
- Findings highlight a substantial impact on QoL, particularly among patients with high surgical burden.
  - Although self-reported data may be subject to recall and reporting bias, consistent trends were observed across domains.
  - Findings from this survey fill a critical gap in understanding the broader burden of RRP across multiple physical and mental health impacts.

- Conclusions: Adult patients with RRP report a substantial physical and mental health burden that impacts overall well-being, work productivity, and overall QoL, particularly in those with frequent surgeries.**
- These findings highlight the need for targeted therapies to reduce disease burden and improve patient outcomes.**

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## CONTACT INFORMATION

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