

# Understanding Head and Neck Schwannoma and Paraganglioma Patient Experiences Through Social Media

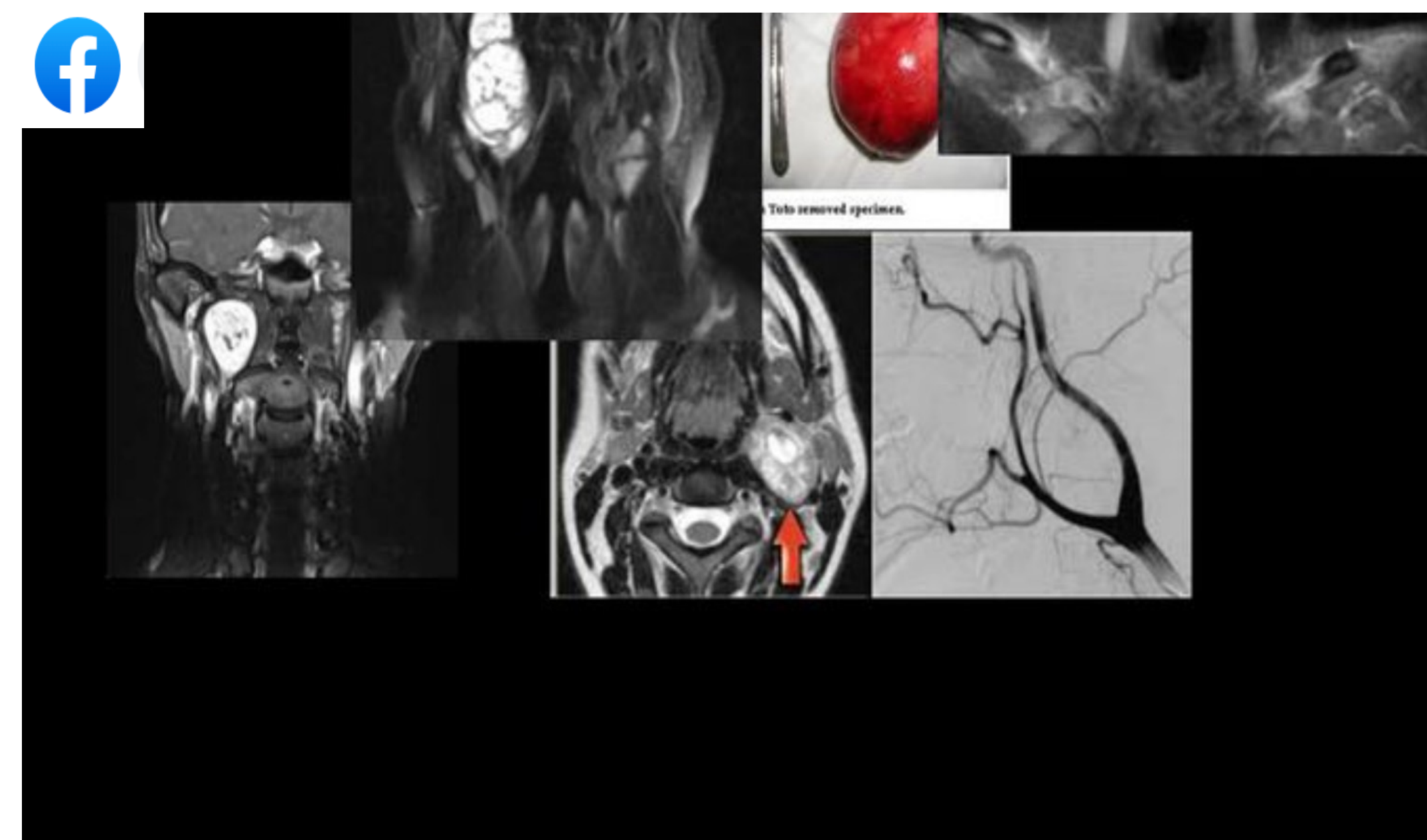
Madelyn N. Stevens MD, Jaclyn Lee MD, Rhonda Edwards, James L. Netterville MD  
Department of Otolaryngology - Head & Neck Surgery, Vanderbilt University Medical Center, Nashville, TN

## INTRODUCTION

- Social media provides a unique opportunity to connect geographically disparate individuals and serve as a platform for community building and resource sharing<sup>1,2</sup>
  - For rare diseases in particular, finding in-person groups can be difficult
- There are opportunities for clinicians to gain further insights into patient experiences via social media<sup>3,4</sup>
- Research into the use of patient-focused social media to study rare diseases is limited within the otolaryngology literature
- Here, we investigate experiences of patients with rare benign head and neck tumors using a large online platform

## METHODS

- Cross-sectional survey study of the largest social media group for Head and Neck Schwannomas
  - Patient-run Facebook group with over 1300 international members intended to share advice and experiences
- All members in the group were invited to answer an anonymous survey in February 2022 and March 2023
- Survey questions included demographics, diagnosis, treatment, and use of online resources



Schwannoma's of the head/neck and body - [www.vagalschwannoma.com](http://www.vagalschwannoma.com)

Image 1: Heading for the social media group utilized for survey recruitment

## RESULTS

Age, years, median (IQR)	53 (44, 62)
Age at Diagnosis, years, median (IQR)	48 (39, 57)
Sex, female, n (%)	249 (83%)
Country/Continent of Origin:	
United States	198 (66%)
North American (non-US)	27 (9%)
Europe	49 (16%)
Africa	2 (1%)
Asia	6 (2%)
Australia/New Zealand	15 (5%)
Imaging used for diagnosis, n (%)	293 (98%)
MRI	280 (98%)
CT	107 (36%)
Ultrasound	49 (16%)
Needle Biopsy for diagnosis, n (%)	80 (27%)
Excisional Biopsy for diagnosis, n (%)	16 (5%)
Largest Tumor Dimension, cm, median (IQR)	2.9 (1.9, 4)

Table 1: Survey respondent demographics and initial work up for tumor

Figure 1: Self-reported type of head and neck tumor

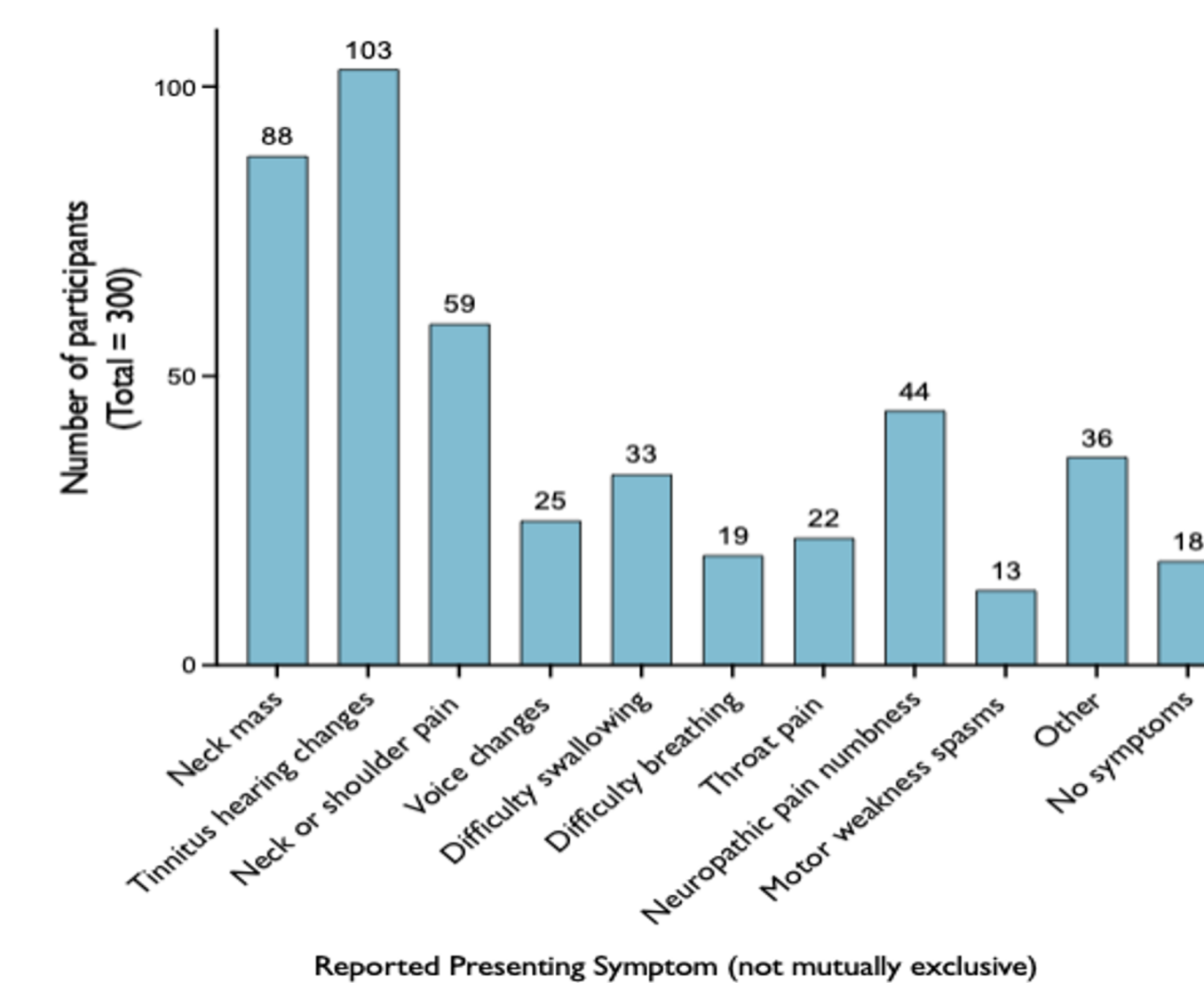
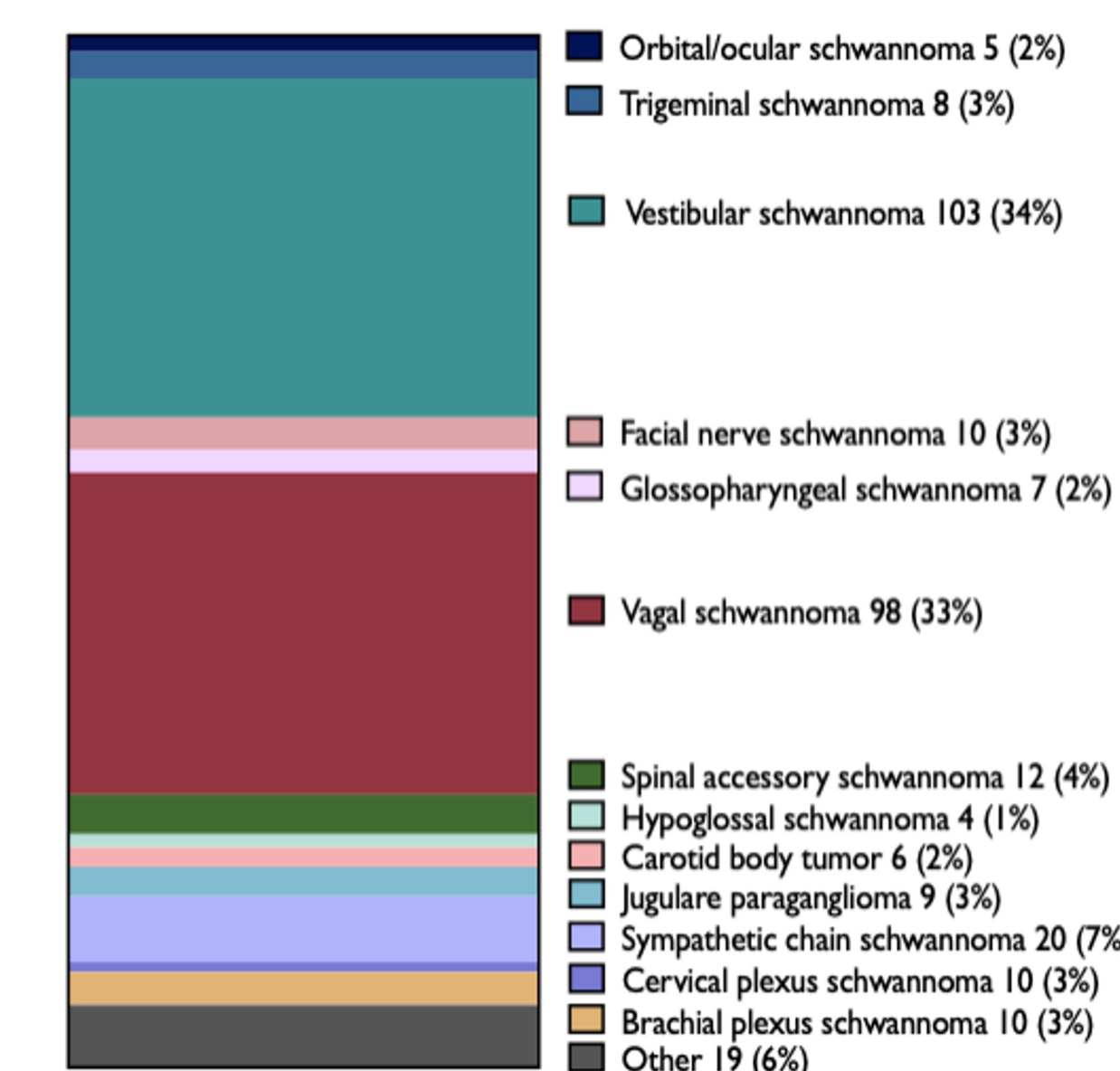


Figure 2: Self-reported initial presenting symptom(s)

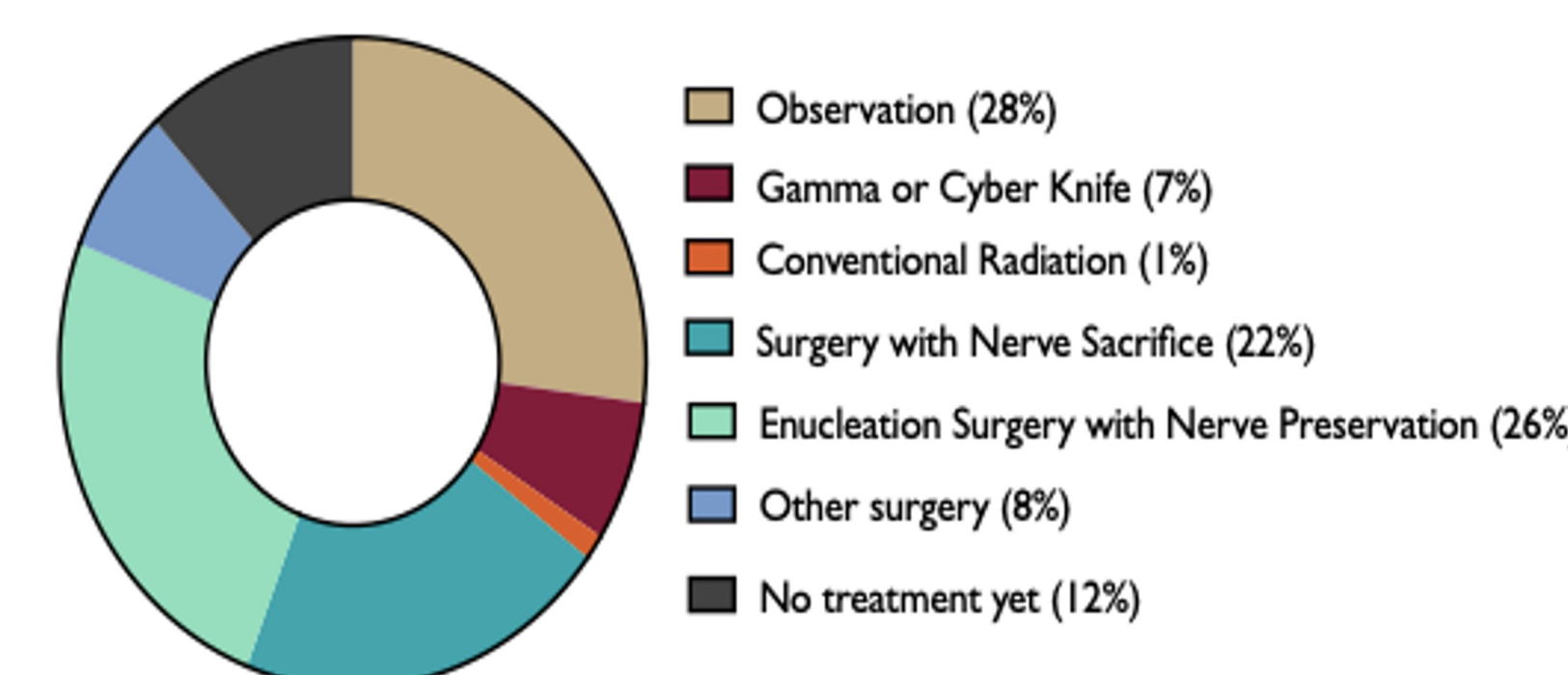


Figure 3: Self-reported treatment choice

## RESULTS

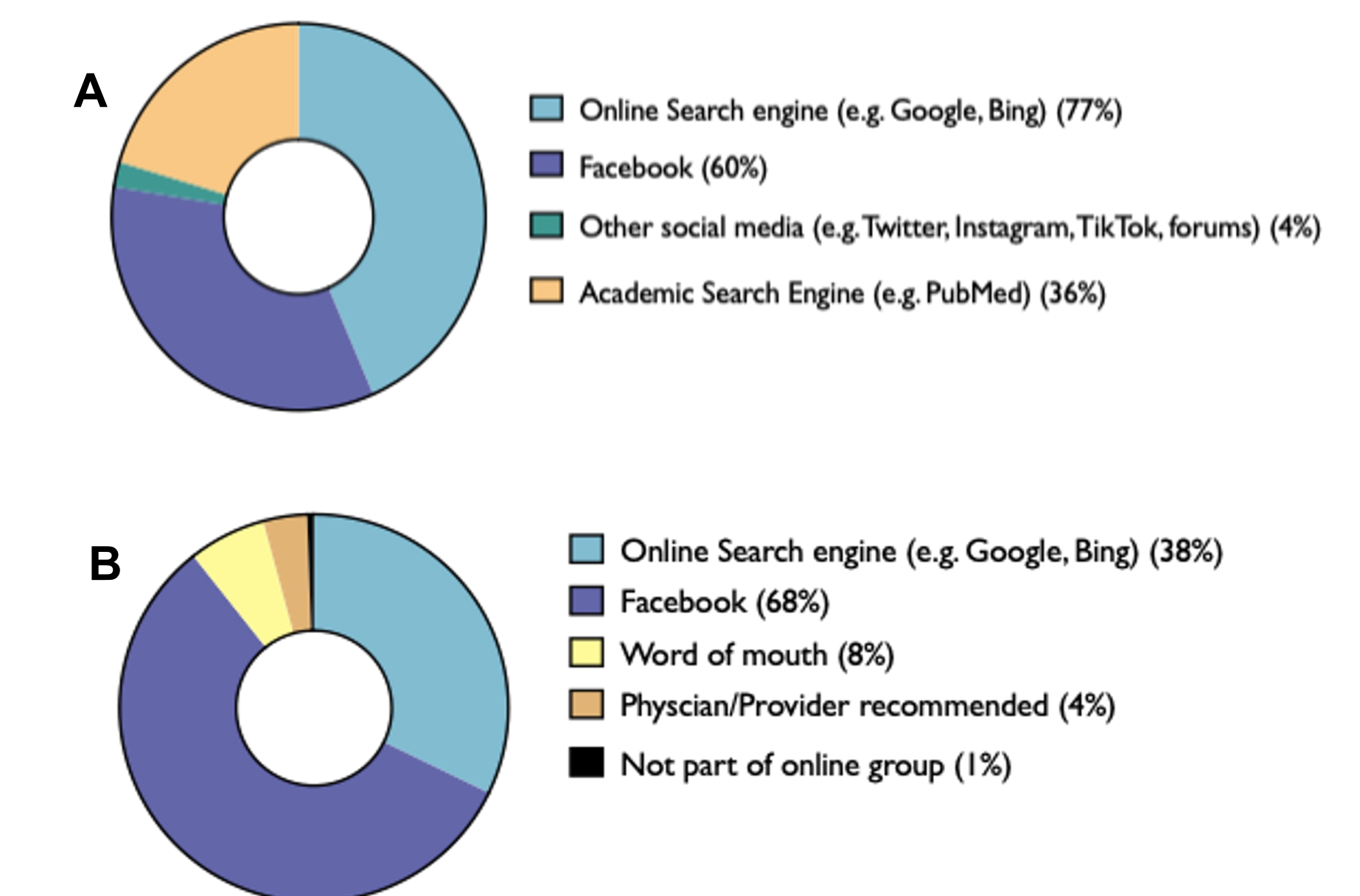


Figure 4: (A) Tools used to find information about patients' diagnosis and (B) Tools used to identify other individuals with the disease

## DISCUSSION

- Successfully reached a large, global sample of patients with a variety of rare tumors, although likely non-representative
- Most common tumors were vagal schwannoma (33%) and vestibular schwannoma (34%)
- Most common presenting symptoms were tinnitus (n=103) and neck mass (n=88)
- Treatment included surgical enucleation, nerve sacrifice, observation, and gamma knife
- Online resources were utilized by a high percentage of respondents for information gathering and community building, with search engines and Facebook being the most common
- Social media is ever evolving (i.e. changes to Twitter, rise of Tiktok) and further research needed to identify how best to support patients via social media

### References

Chen J, Wang Y. Social Media Use for Health Purposes: Systematic Review. J Med Internet Res. 2021 May 12;23(5):e17917  
 Miller EG, Woodward AL, Flinchum G, Young JL, Tabor HK, Halley MC. Opportunities and pitfalls of social media research in rare genetic diseases: a systematic review. Genet Med. 2021 Dec;23(12):2250-2259  
 Davies W. Insights into rare diseases from social media surveys. Orphanet J Rare Dis. 2016 Nov 9;11(1):151  
 Titgemeyer SC, Schaaf CP. Facebook Support Groups for Pediatric Rare Diseases: Cross-Sectional Study to Investigate Opportunities, Limitations, and Privacy Concerns JMIR Pediatr Parent 2022;5(1):e31411

**Acknowledgements:** The authors would like to thank the participants of the Head and Neck Schwannoma Facebook group for their interest and contribution to this study.

**Contact:** Madelyn N. Stevens MD; Email: [stevens.476@gmail.com](mailto:stevens.476@gmail.com)