

# MENTAL HEALTH AND TREATMENT OF PATIENTS WITH IMMUNE THROMBOCYTOPENIA (ITP); DATA FROM THE PLATELET DISORDER SUPPORT ASSOCIATION (PDSA) PATIENT REGISTRY

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## 1. BACKGROUND AND AIMS

Patients with the autoimmune disease ITP suffer from bleeding events as a result of low platelet counts. These events may manifest as bruises, petechiae, blood blisters, bloody stools, blood in urine, or even bleeding in the brain. Treatments vary by severity of disease but include medications (immunosuppressives, IVIG, platelet boosters) and splenectomy. Both the disease and the treatments impact quality of life for these patients, who commonly state concerns of anxiety and fatigue. In 2017, PDSA in collaboration with NORD launched the ITP Natural History Registry to understand patient characteristics, their disease, disease management, and quality of life. Here, we describe the quality of life for registrants to date, as it relates to mental health and treatment.

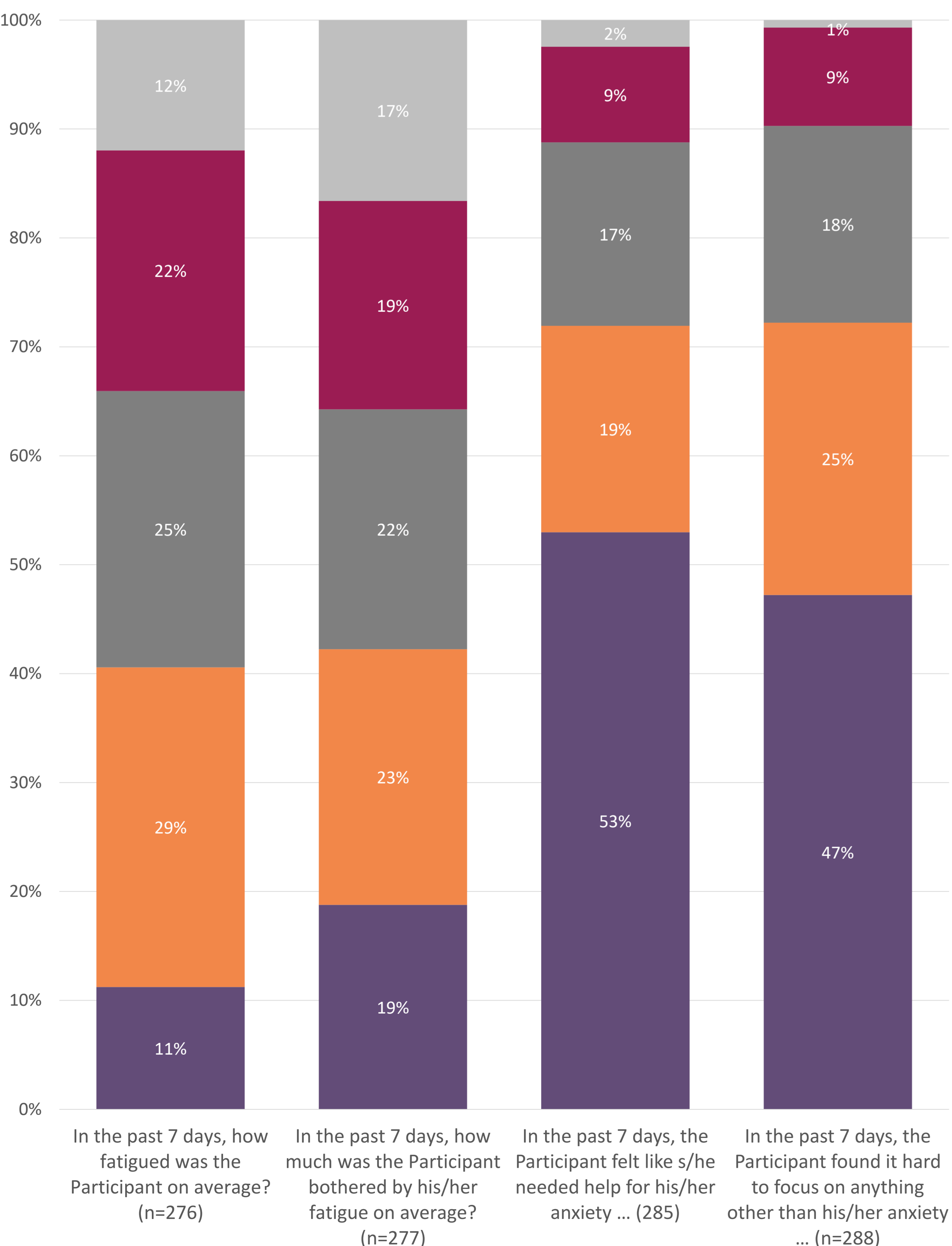
## 2. METHODS

The PDSA Registry contains 6 surveys covering patient demographics, medical and diagnostic information, treatment utilization, disease progression, and quality of life. As of February 2019, 538 patients have completed 1,975 surveys.

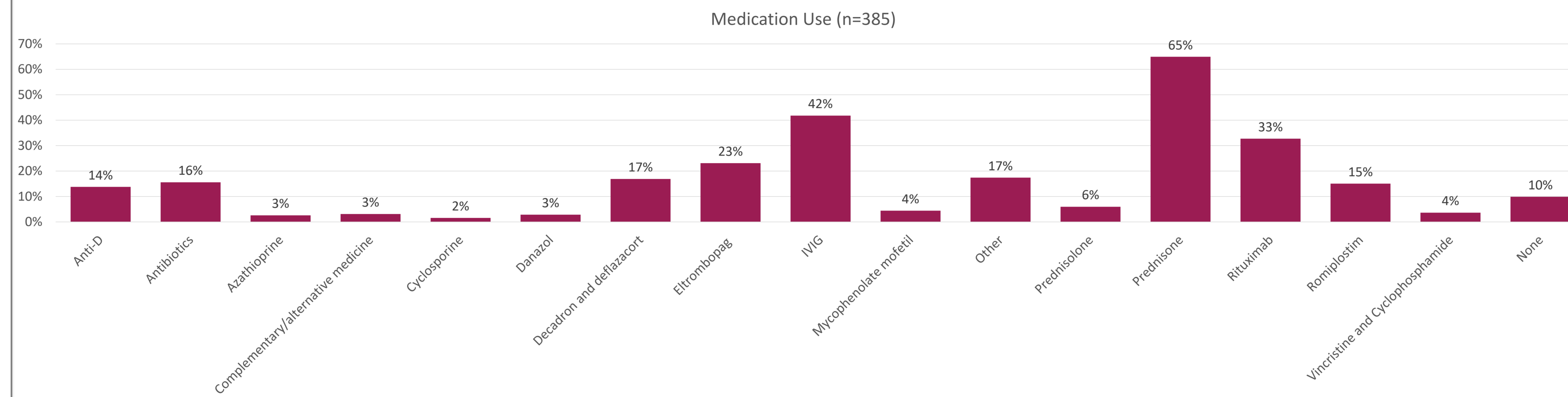
## 3. ANXIETY AND FATIGUE

### PARTICIPANT ANXIETY AND FATIGUE IN THE PAST 7 DAYS

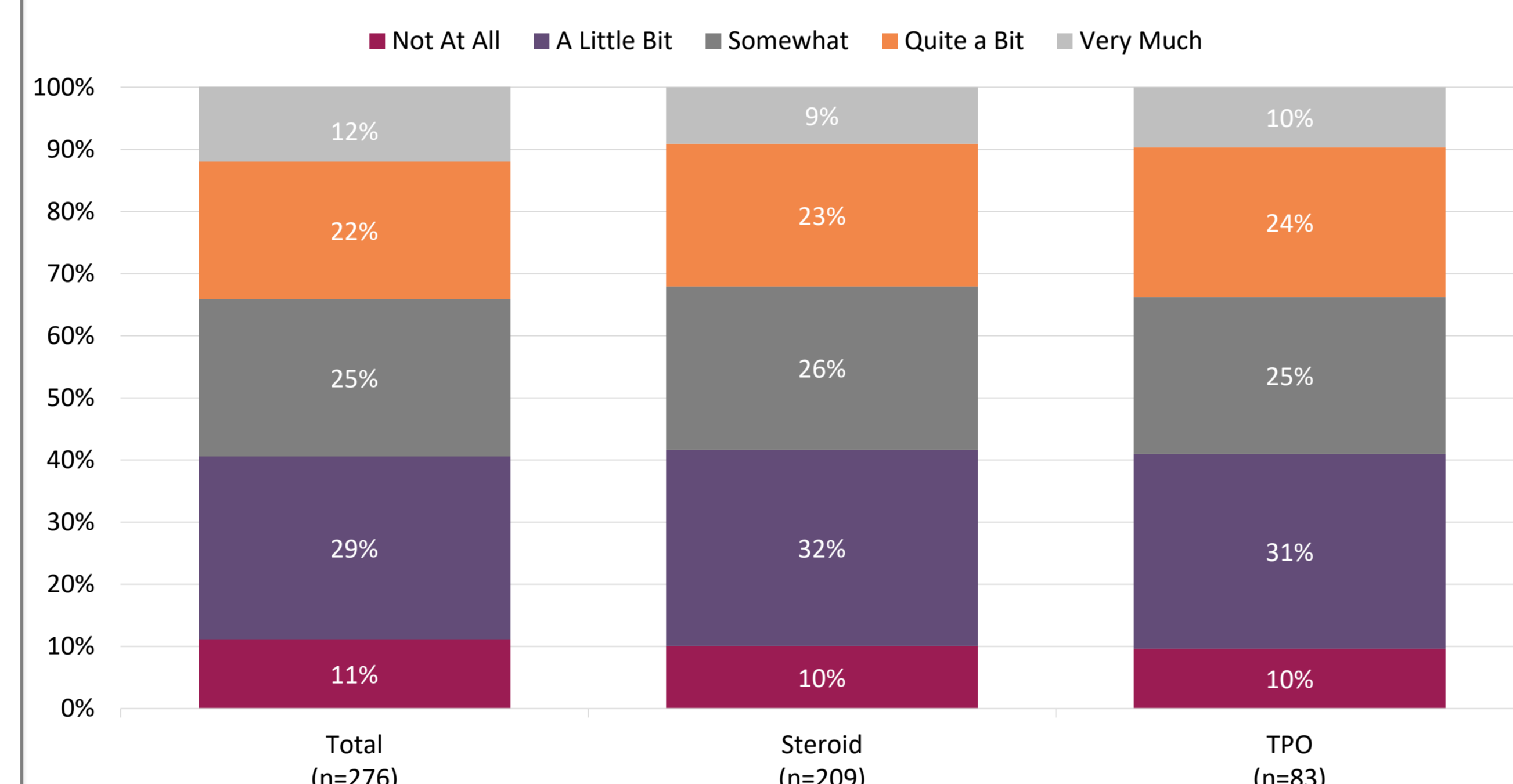
■ Not At All/Never ■ A Little Bit/Rarely ■ Somewhat/Sometimes ■ Quite a Bit/Often ■ Very Much/Always



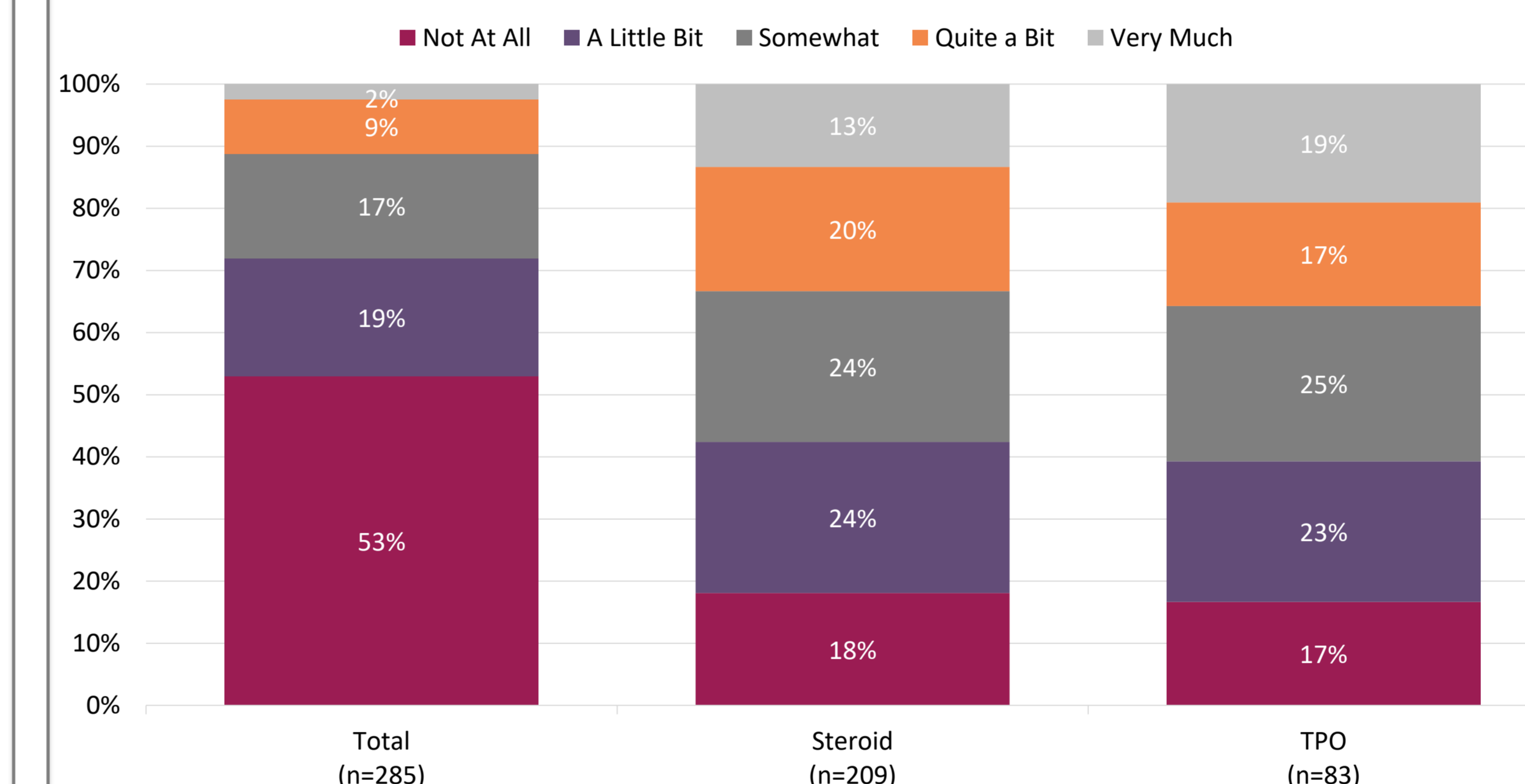
## 5. TREATMENT



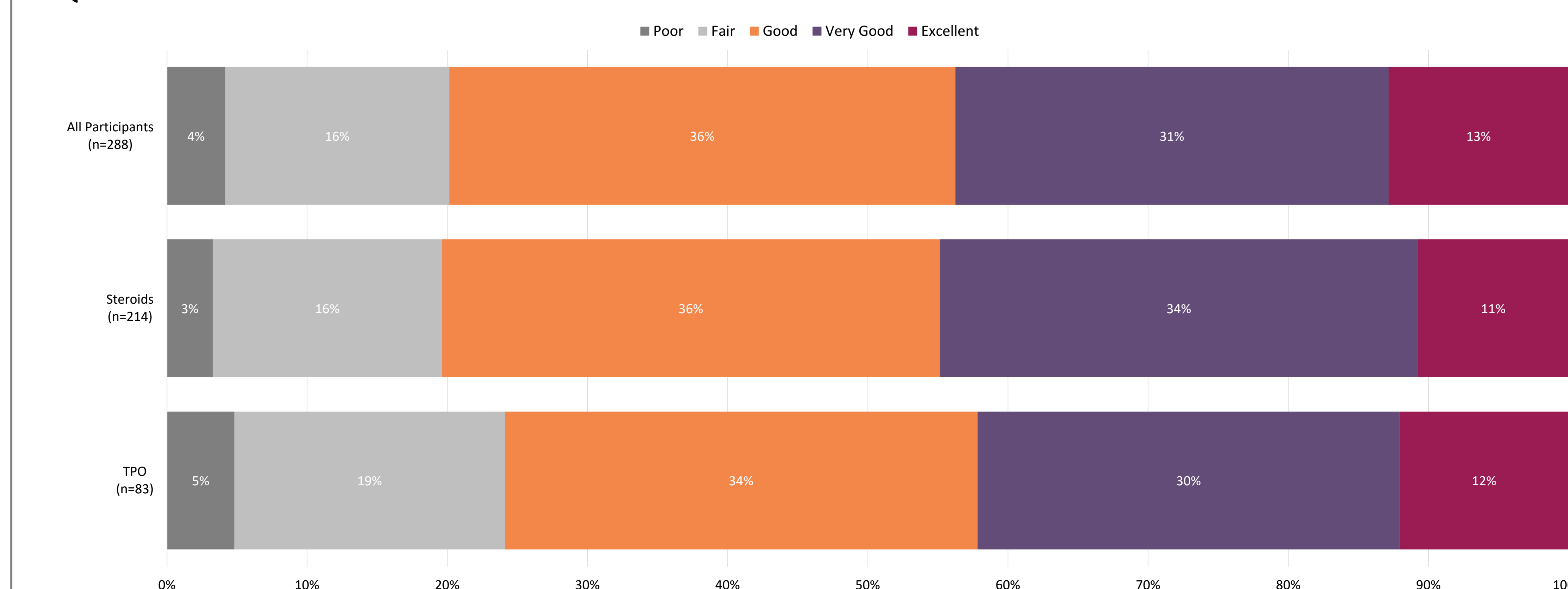
## 6. FATIGUE BY TREATMENT



## 7. ANXIETY BY TREATMENT



## 8. QUALITY OF LIFE BY TREATMENT



## 9. SUMMARY

Patients with the autoimmune disease ITP suffer from bleeding events as a result of low platelet counts. These events may manifest as bruises, petechiae, blood blisters, bloody stools, blood in urine, or even bleeding in the brain. Both the disease and the treatments impact quality of life for these patients, who commonly state concerns of anxiety and fatigue. In 2017, PDSA in collaboration with NORD launched the ITP Natural History Registry to understand patient characteristics, disease, disease management, and quality of life. Here, we describe the quality of life for registrants to date.

### Anxiety and Fatigue

- 89% (245/276) of patients were fatigued within the past 7 days.
- 81% (225/277) of participants were bothered by fatigue in the past 7 days.
- 47% (134/285) of participants reported feeling like they needed help with their anxiety within the past 7 days.
- 53% (152/288) of participants reported finding it hard to focus on anything other than anxiety within the past 7 days.

### Treatment

- Participants reported the use of 16 different types of medication.
- The most commonly used medication among registry patients is Prednisone (65%, 250/385).
- 10% (38/385) of participants reported that they did not use any medication.

### Fatigue by Treatment

- Participant fatigue did not differ significantly based on medication type.
- The number of participants who use steroids and did not report fatigue was not significantly different than the number of total participants who did not report fatigue ( $z=0.417$ ,  $p=0.674$ , not significant at  $p < 0.05$ ).
- The number of participants who use TPO and did not report fatigue was not significantly different than the number of total participants who did not report fatigue ( $z=0.409$ ,  $p=0.682$ , not significant at  $p < 0.05$ ).

### Anxiety by Treatment

- Participant anxiety did differ significantly based on medication type.
- The number of participants who use steroids and did not report anxiety was significantly different than the number of total participants who did not report anxiety ( $z=7.90$ ,  $p < 0.00001$ , significant at  $p < 0.05$ ).
- The number of participants who use TPO and did not report anxiety was significantly different than the number of total participants who did not report anxiety ( $z=5.88$ ,  $p < 0.00001$ , significant at  $p < 0.05$ ).

### Insurance Coverage

- Quality of life was reported as poor or fair for a number of patients that did not differ significantly by medication type. (Steroid compared to total:  $z=0.142$ ,  $p=0.889$ , not significant at  $p < .05$ ; TPO compared to total:  $z= -0.780$ ,  $p=0.435$ , not significant at  $p < .05$ ).

## 10. CONCLUSION

Data collection continues through the PDSA ITP Natural History Registry with the intent of raising disease awareness and understanding the impact of the disease.