

An Update on Treatment Data from the Desmoid Tumor Research Foundation

Natural History Study

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THE DESMOID TUMOR RESEARCH FOUNDATION



1. BACKGROUND AND AIMS

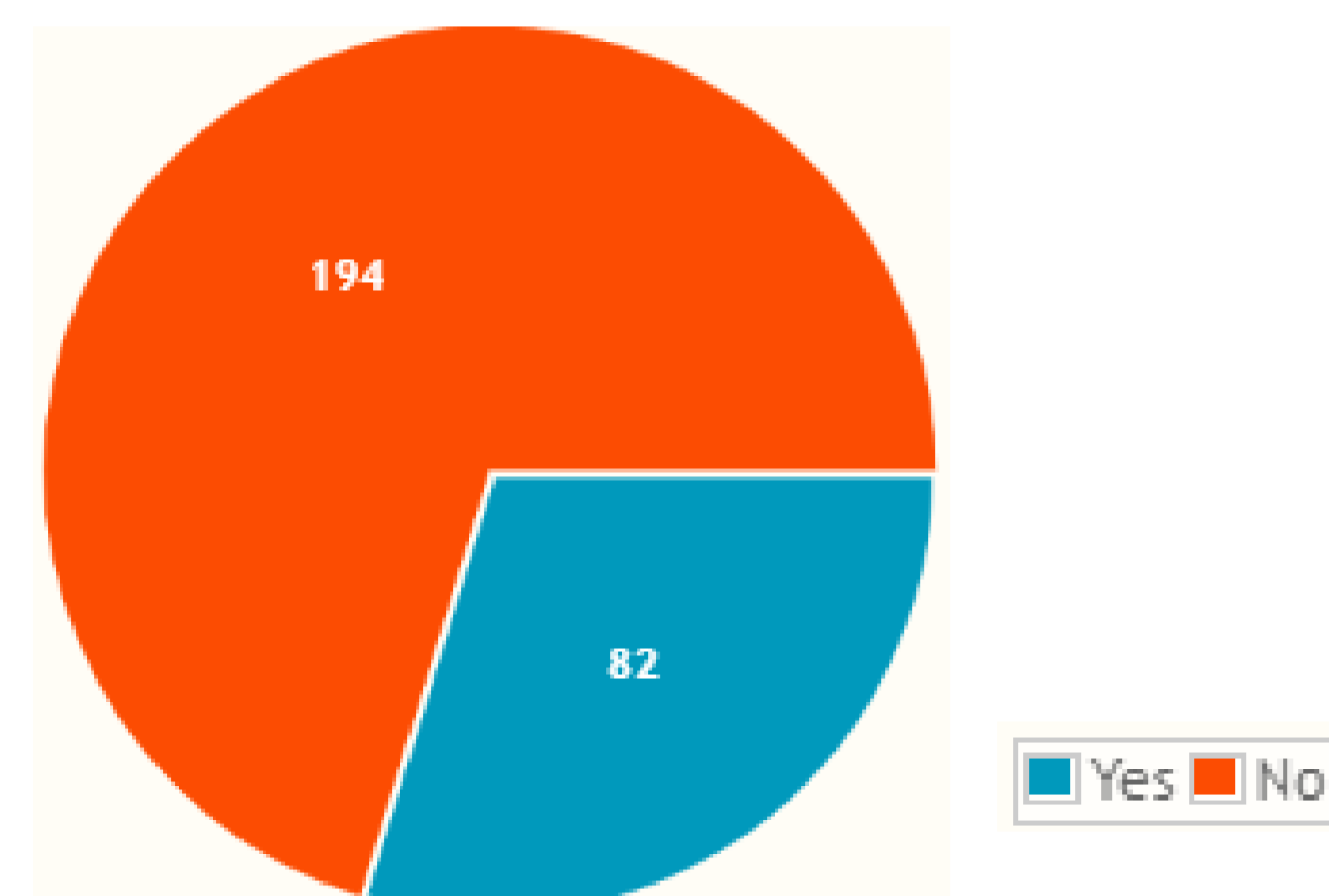
The Desmoid Tumor Research Foundation (DTRF) launched the patient registry and natural history study in 2017. There are many treatment options available to desmoid tumors. Here, we describe the types of treatments and the patient reported outcomes.

2. METHODS

The registry launched in September 2017 and contains 15 surveys covering diagnostics, disease, treatment, care management, and quality of life. As of August 20, 2020, 359 patients or legally authorized representatives have completed the survey on desmoid tumor treatments.

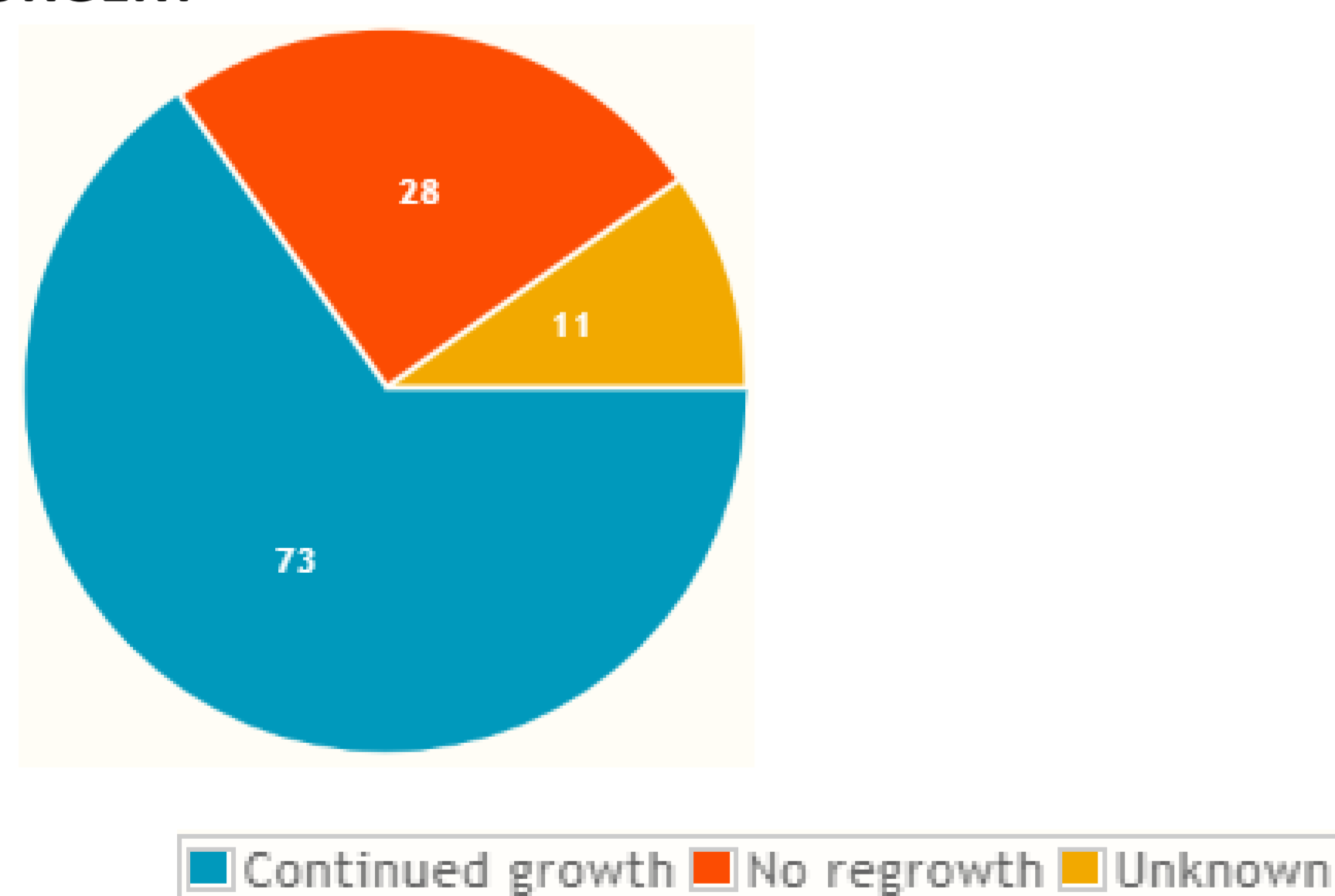
3. DO PARTICIPANTS RECEIVE MORE THAN 1 TREATMENT?

N=276



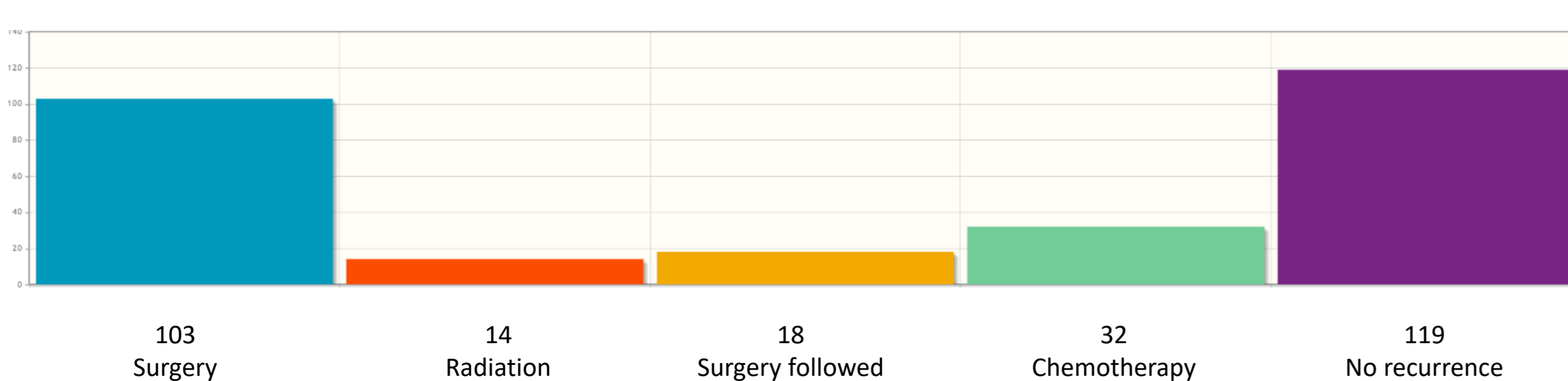
4. RESPONSE TO SURGERY

N=112



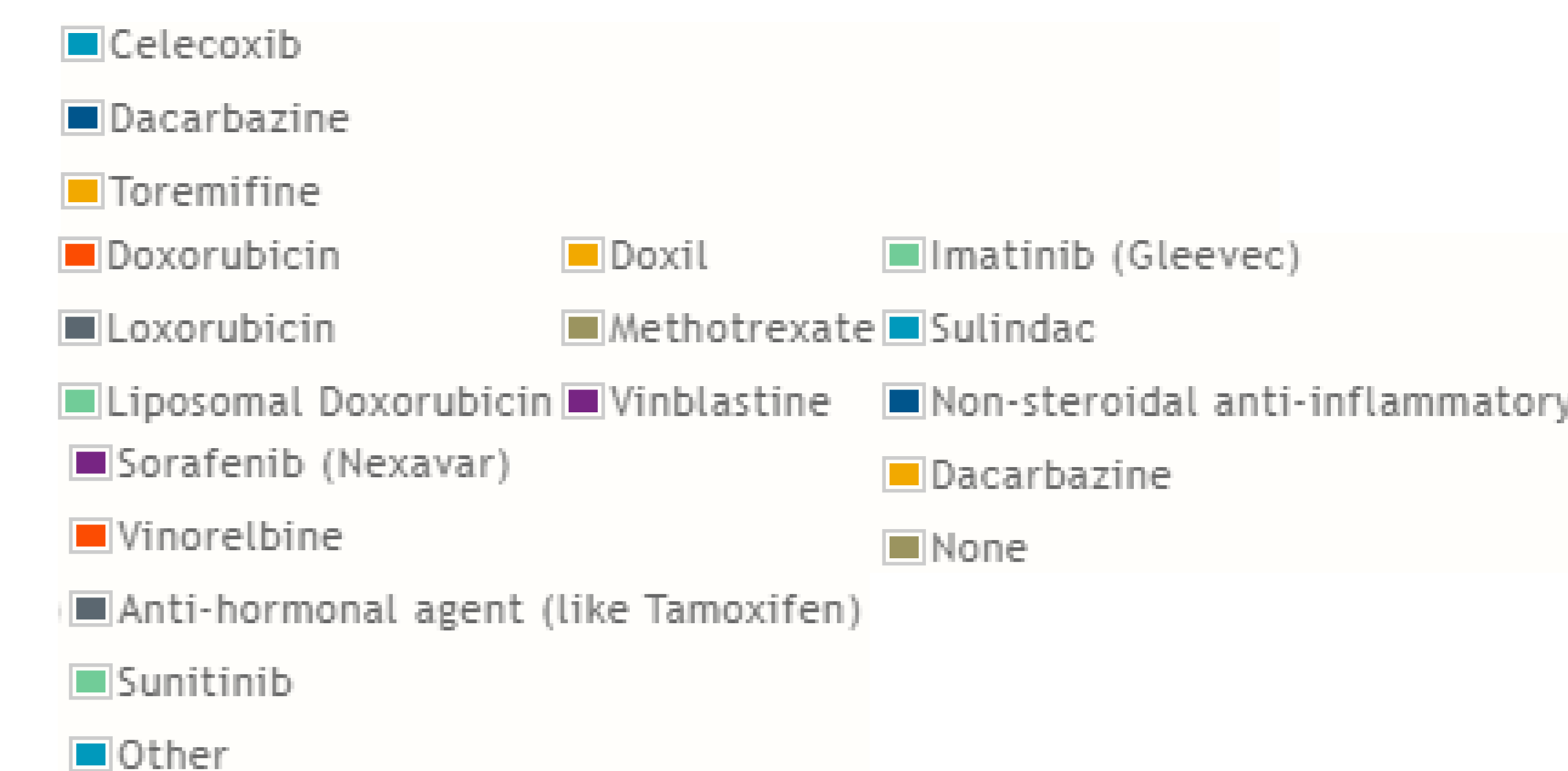
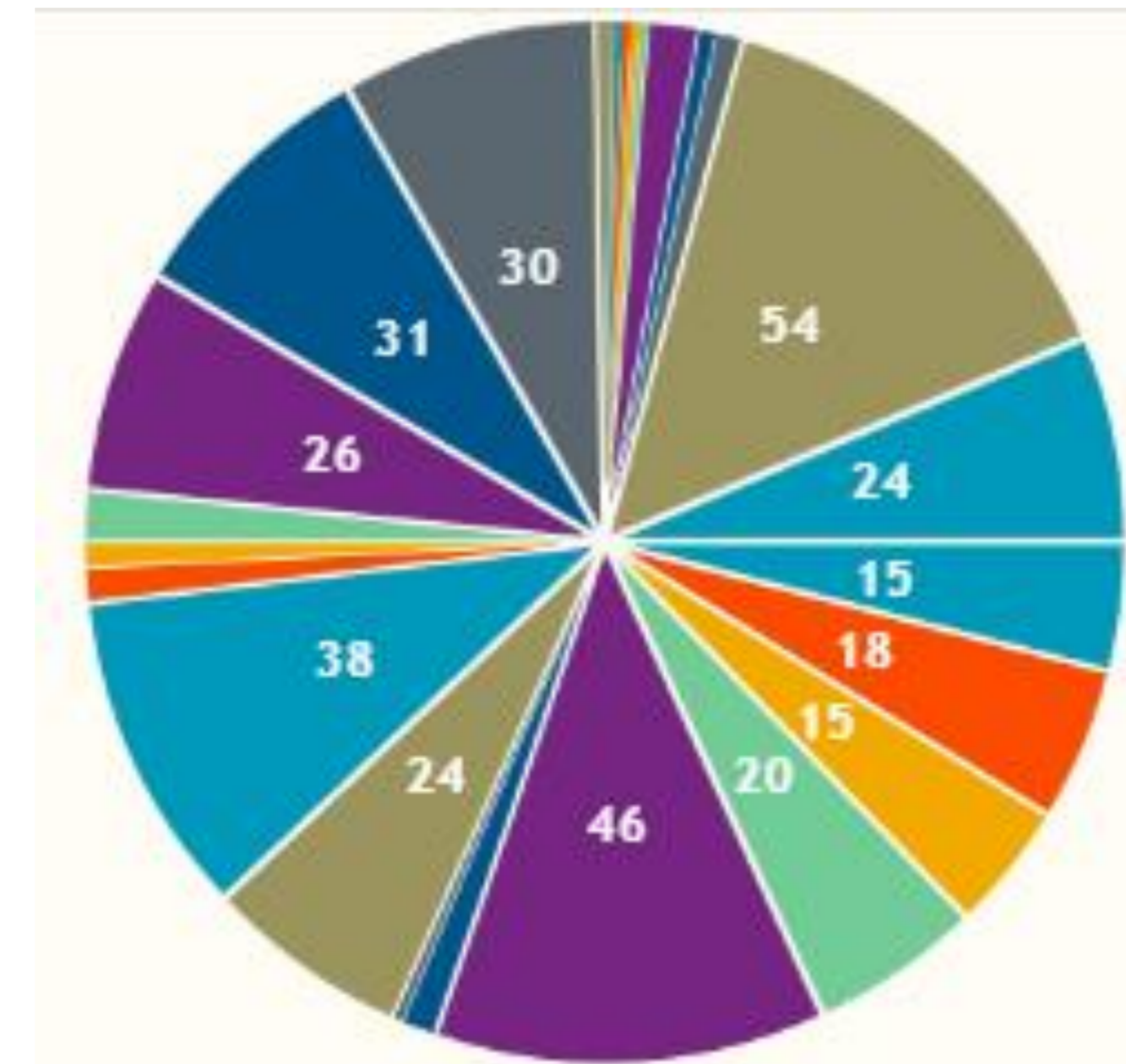
5. POST-TREATMENT DISEASE RECURRENCE AND NON-RECURRENCE

N=286



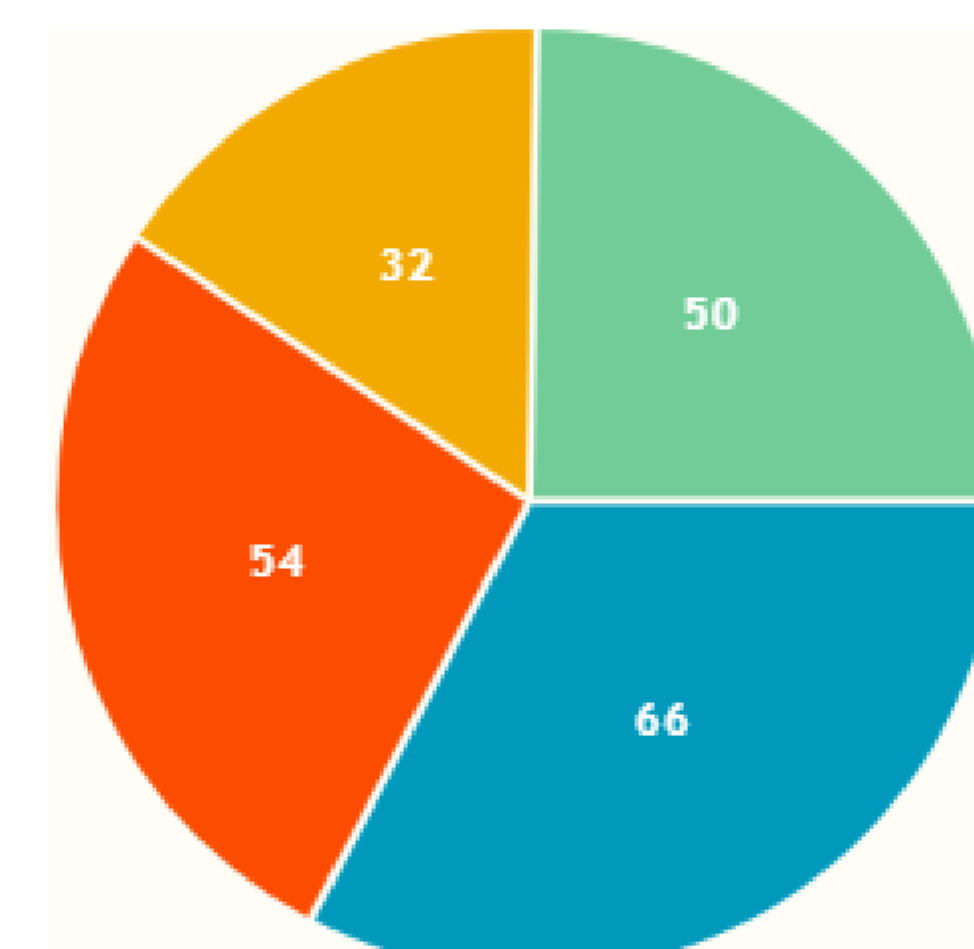
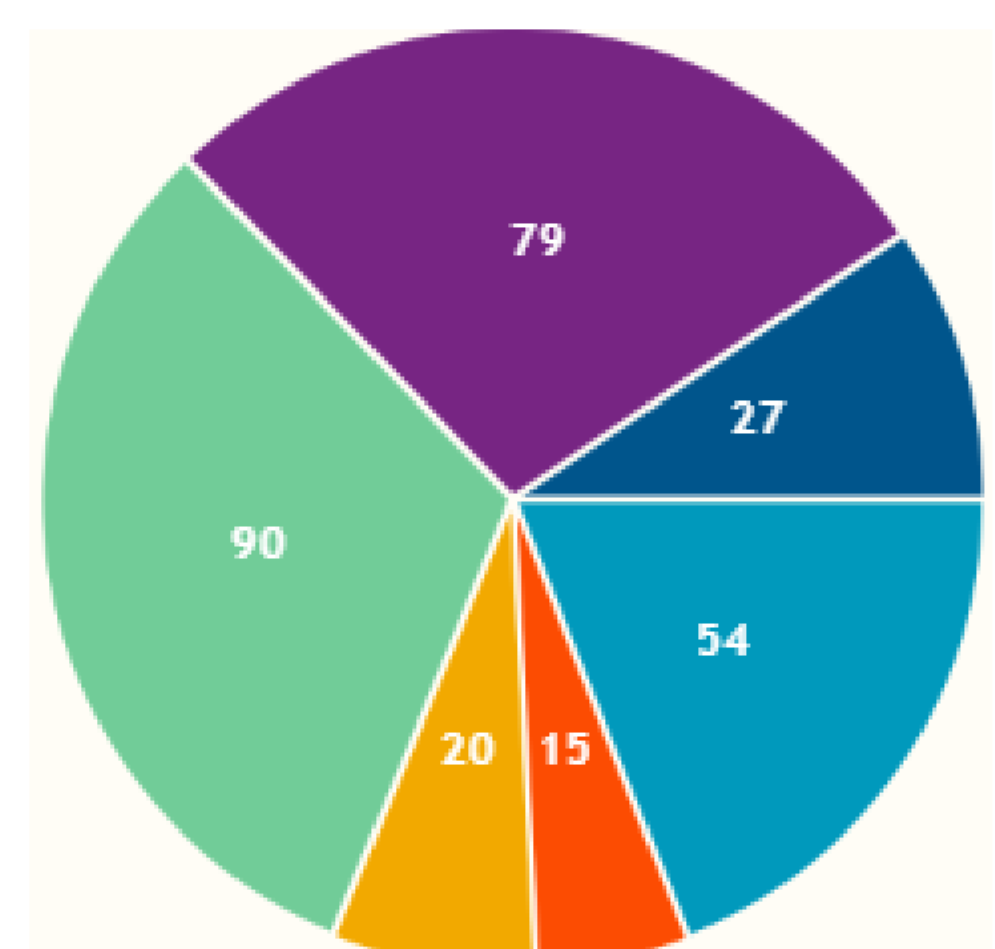
6. ALL MEDICATIONS THAT THE PARTICIPANTS HAVE TAKEN OR ARE TAKING

N=376



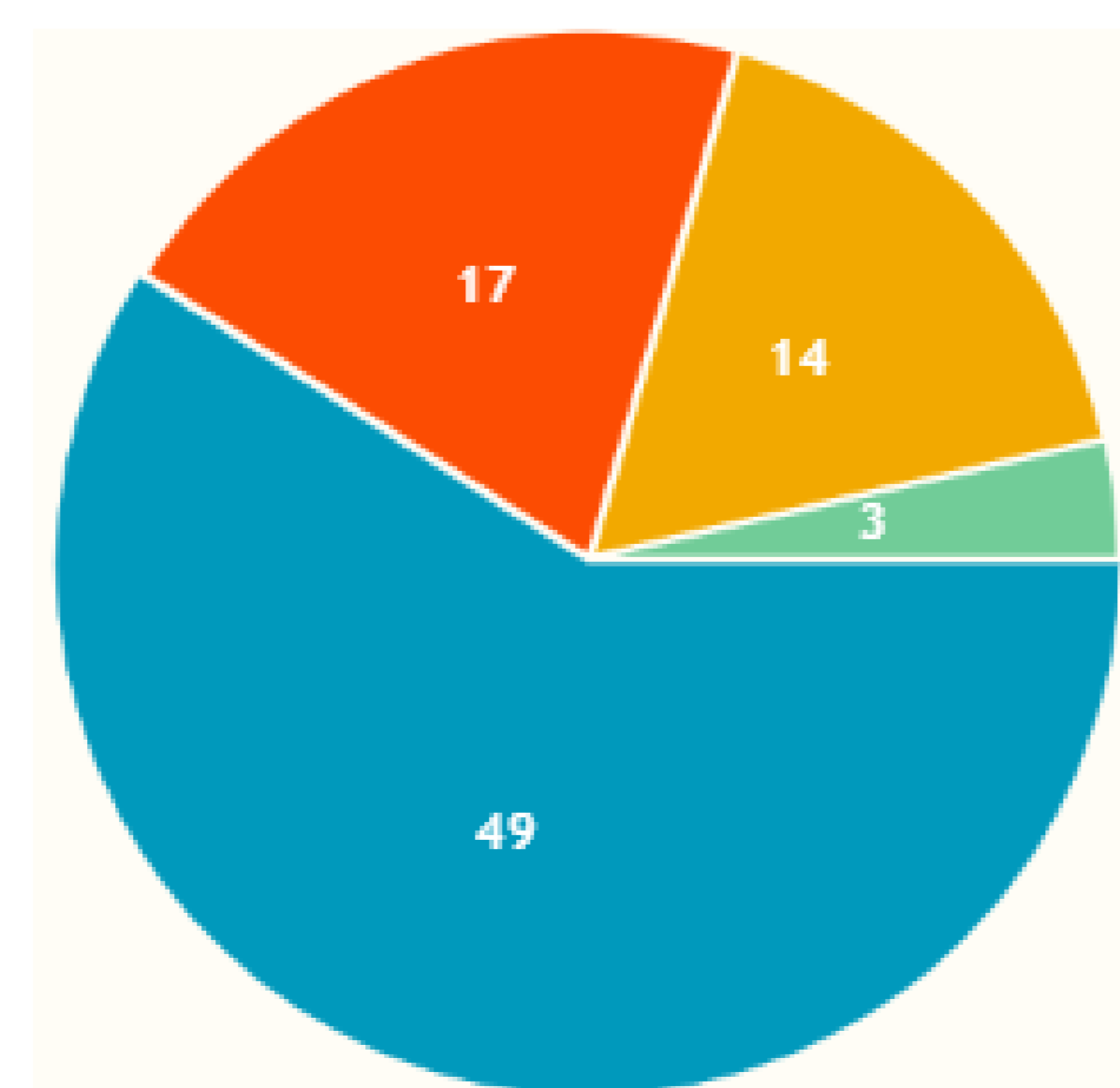
7. ADDITIONAL TREATMENT TYPES AND RESPONSE

N=285, 202

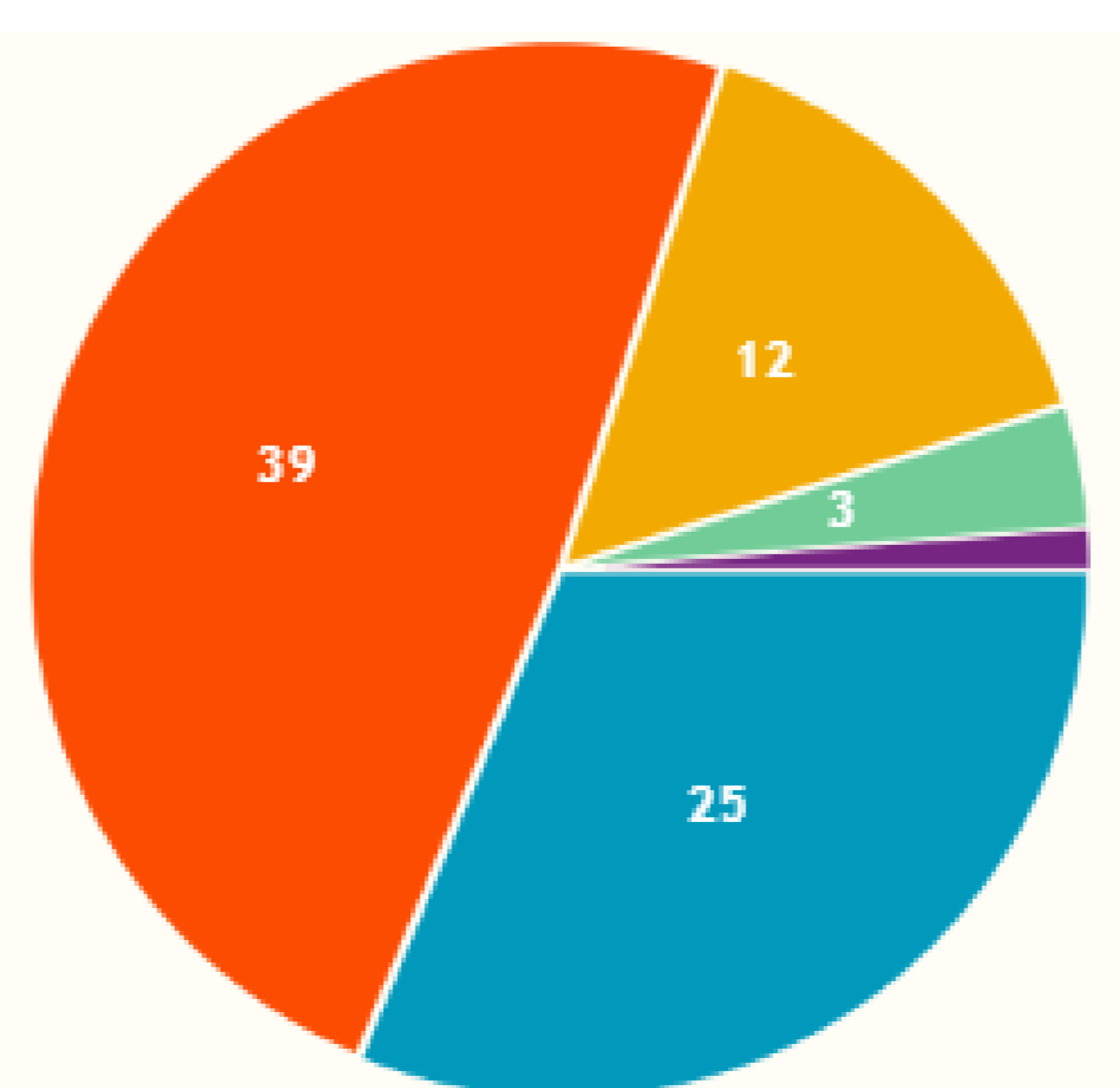


8. TREATMENT SEQUENCING

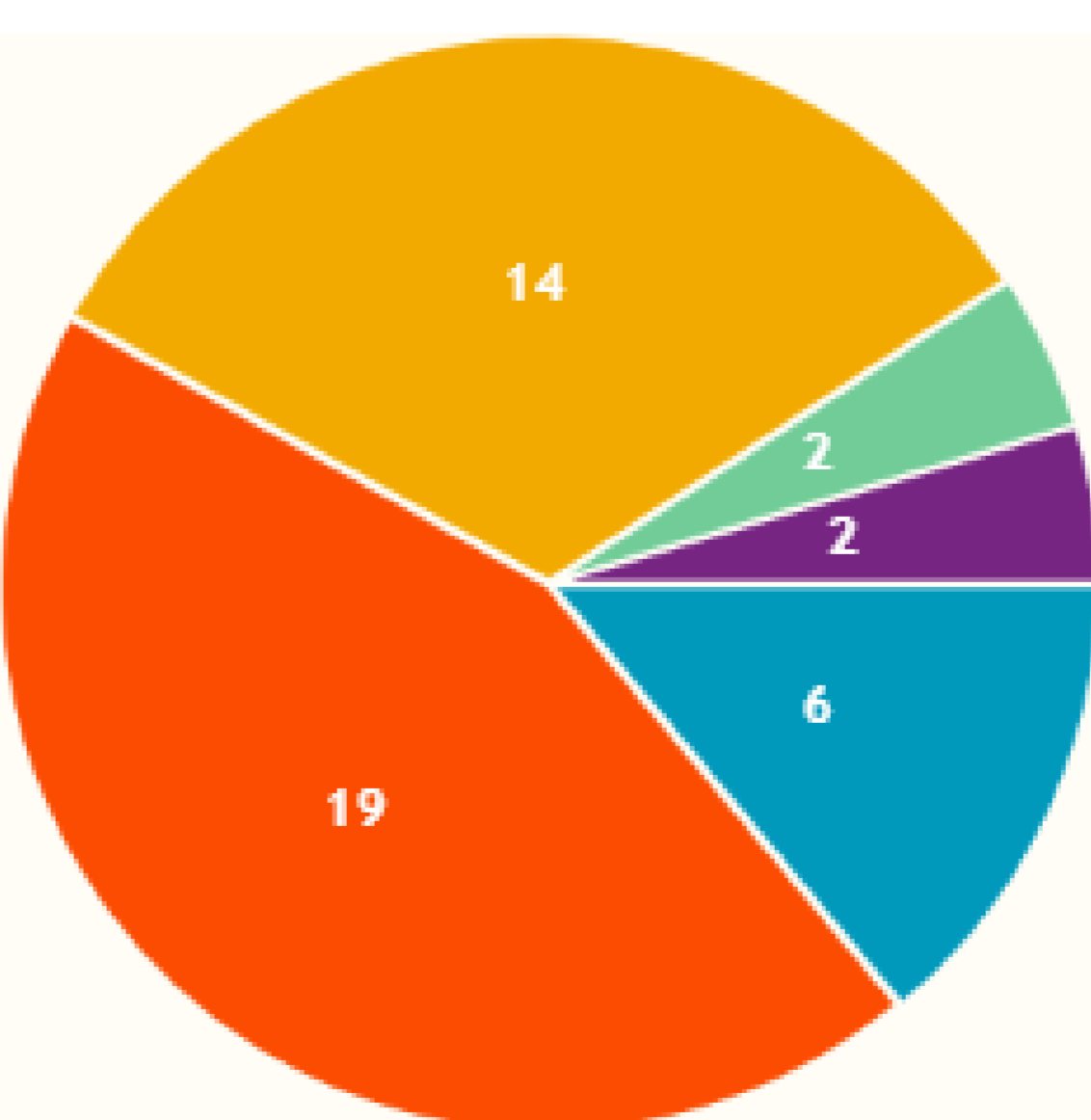
What was the first treatment given? (N: 83)



What was the second treatment given? (N: 80)

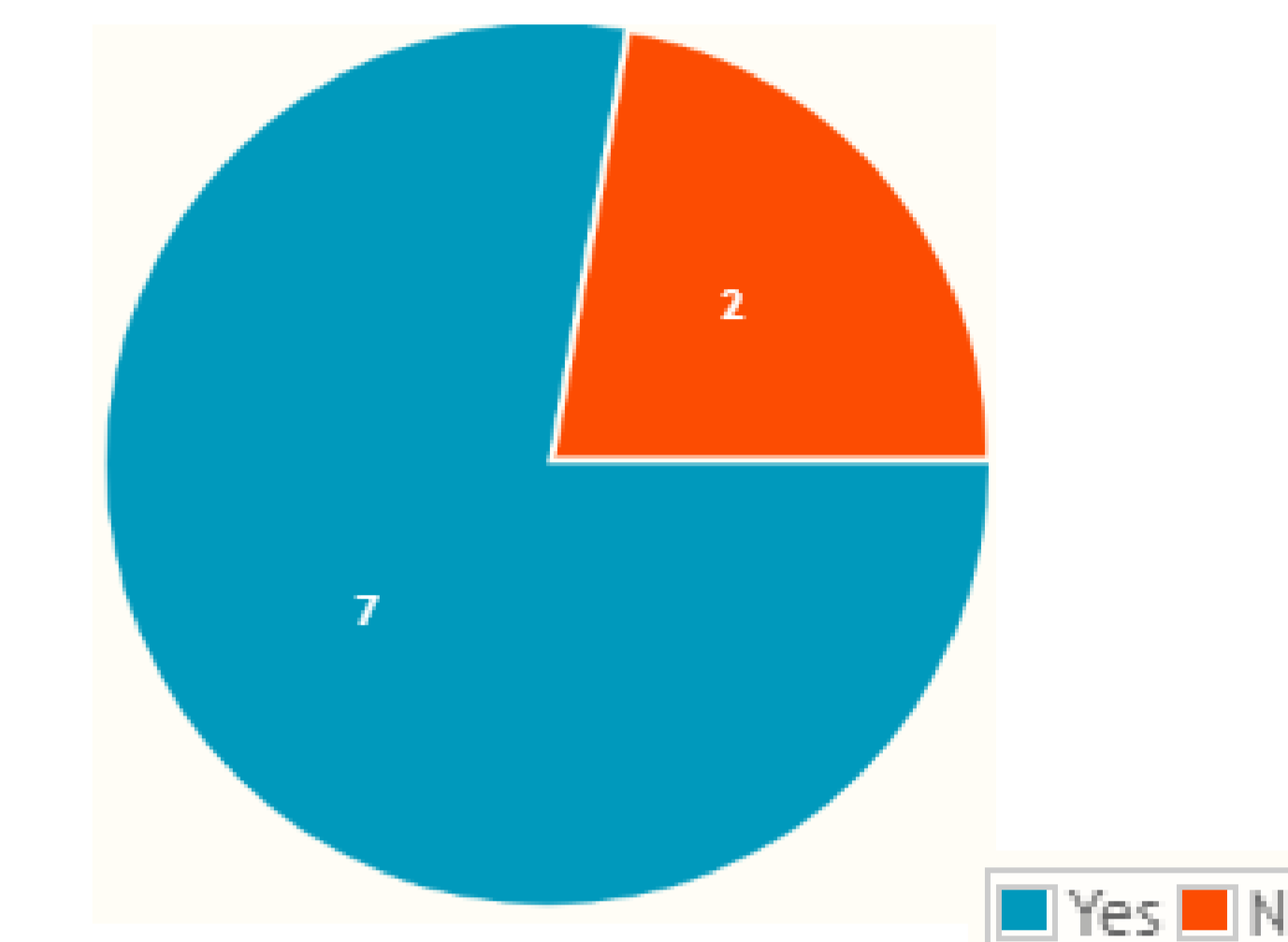


What was the third treatment given? (N: 43)



9. RECURRENCE FOLLOWING AN AMPUTATION

N=9



10. SUMMARY

Multiple treatments

- 30% of participants reported that they have received more than one treatment.

Surgical response

- 65% of participants reported the tumor continued to grow after surgery.

Recurrence following surgery

- 42% of participants reported no recurrence after treatment.
- Out of 167 participants who reported recurrence after treatment, 103 (62%) reported that their tumor has recurred after surgery.

All systemic medications

- There is a wide variety of systemic treatments prescribed to the participants, indicating that there is no standard of care currently.
- The most commonly prescribed medications were none, sorafenib, and anti-hormonals (Tamoxifen).

Additional treatment types and response rates

- Approximately 32% of participants reported that the Watch and Wait approach has been utilized as an additional treatment type.
- Regarding the response, approximately 33% of participants reported that the tumor has continued to grow.

Sequencing of Treatments

- 59% of participants reported that surgery was their first treatment.
- Alternative treatments were more common in the 2nd and 3rd line.

Recurrence following an amputation

- Approximately 78% of participants reported that their tumor has recurred following an amputation.

12. ACKNOWLEDGEMENTS

The DTRF NHS is supported through the generous contributions to the DTRF and a cooperative agreement between the National Organization of Rare Disorders (NORD) and the FDA (PI Pamela Gavin). The authors sincerely thank NORD for their support and most humbly thank the desmoid tumor patients, caregivers, and support systems for their personal medical data, without which this study would not be possible.