

2013 National Treatment Survey

Immune Deficiency Foundation



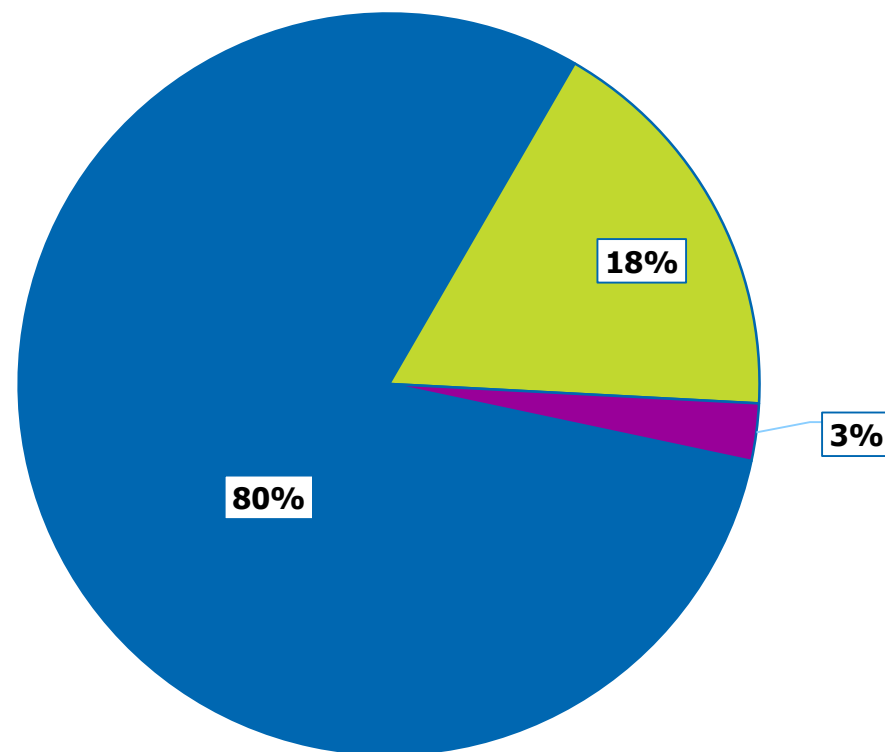
IDF 2013 Treatment Survey

- Mail-based, pencil & paper survey
 - Over 75 Main questions
- Survey in the field December 2013-March 2014
- IDF mail invitation to 4,000 individuals from IDF's database identified as either a patient or a parent or a patient with a PI
- Second e-mail invitation sent January 27, 2014 to non-respondents
- Survey closed on Monday March 31, 2014
- 1,608 completed the survey
 - Traditional survey would place the expected survey sampling error at +/- 2.4% for the full sample at the 95% Confidence Level
- Data from patients that are currently using IVIG or SCIG will be presented on the following slides



Patient or Parent/Caregiver

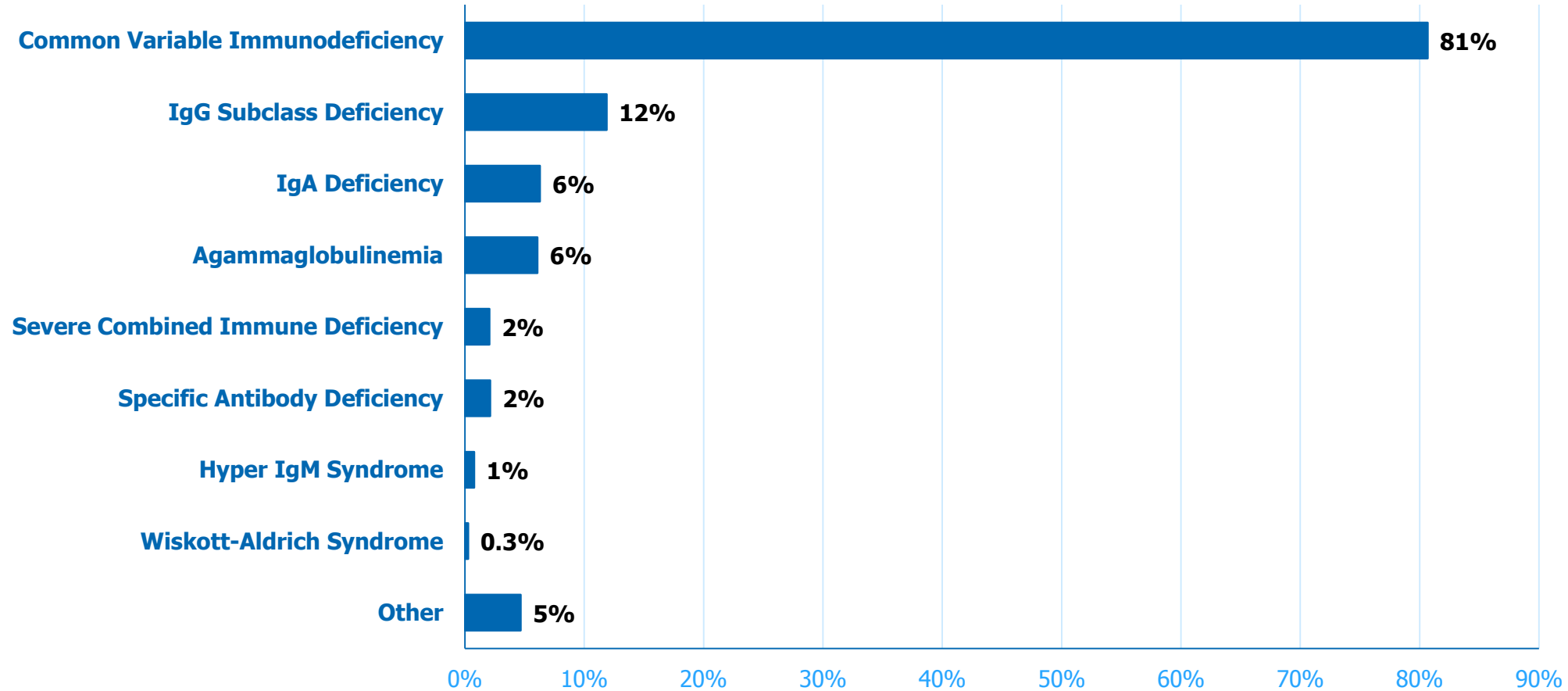
■ PI Patient ■ Parent/caregiver ■ Both



Q1. Are you a patient with a primary immunodeficiency disease (PI) or parent/caregiver of a child in the household with PI? N=1,425
Base: Respondents that are currently receiving IVIG or SCIG



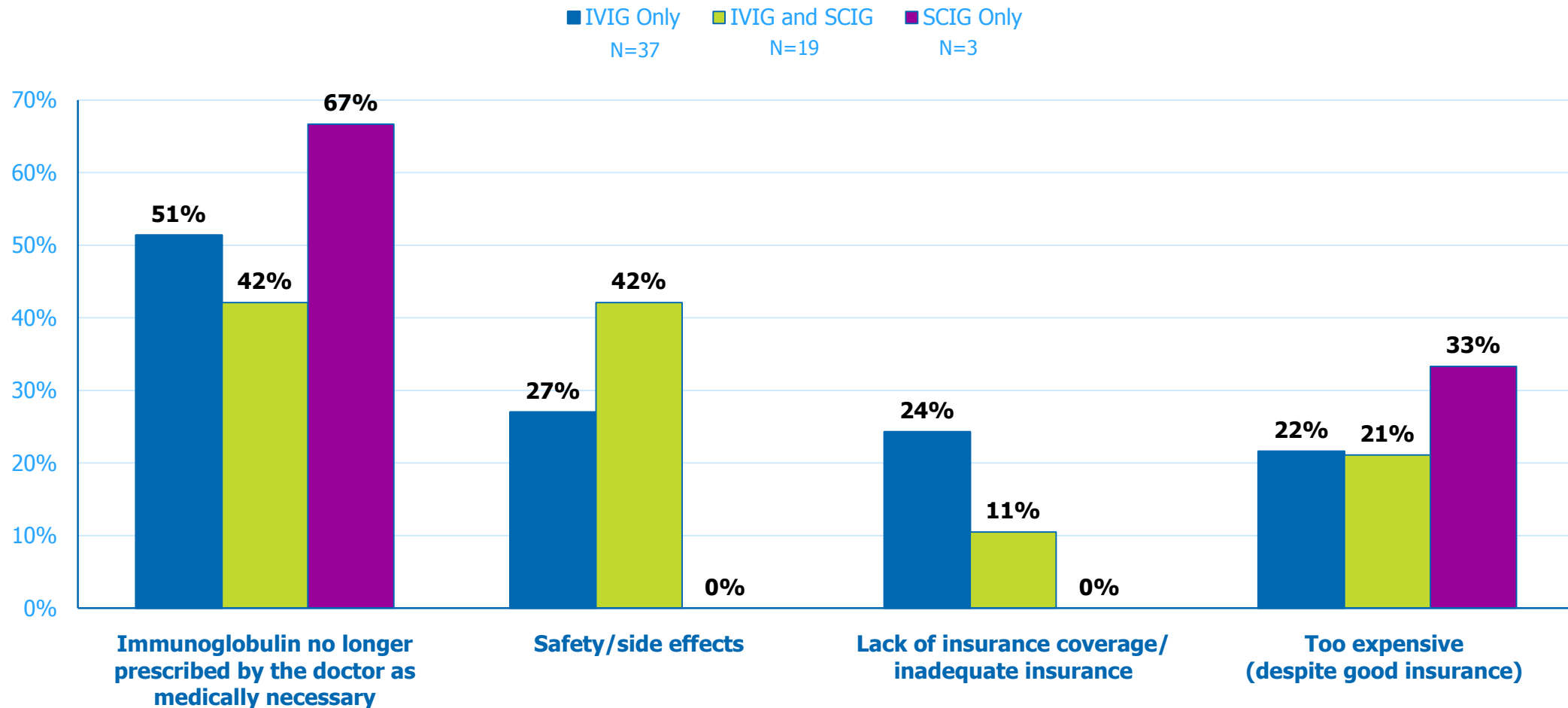
PI Diagnosis



Q5. What is the specific diagnosis of that person's immunodeficiency disease? N=1,412
Base: Patients who currently use IVIG or SCIG



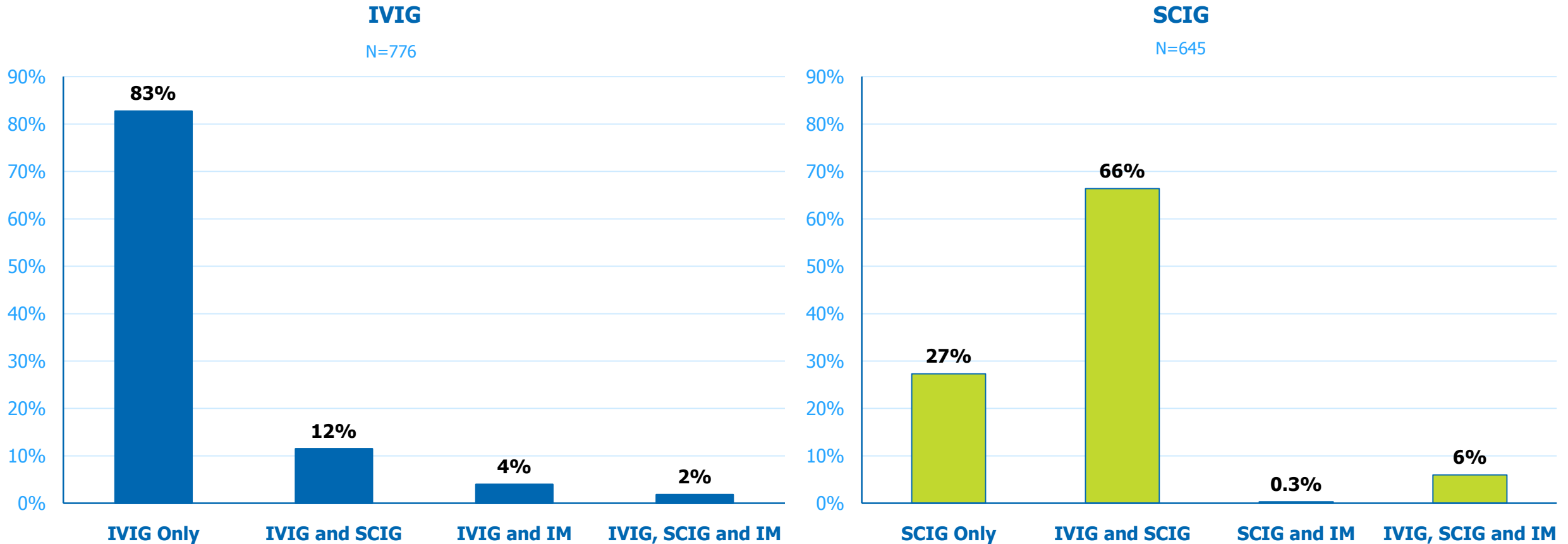
No Longer Using Ig Therapy



Q21b. Why is the patient no longer being treated with immunoglobulin? SELECT ALL THAT APPLY
Base: Patients who stopped using Ig therapy



Ig Therapy: Has the Patient EVER Used... IVIG vs. SCIG

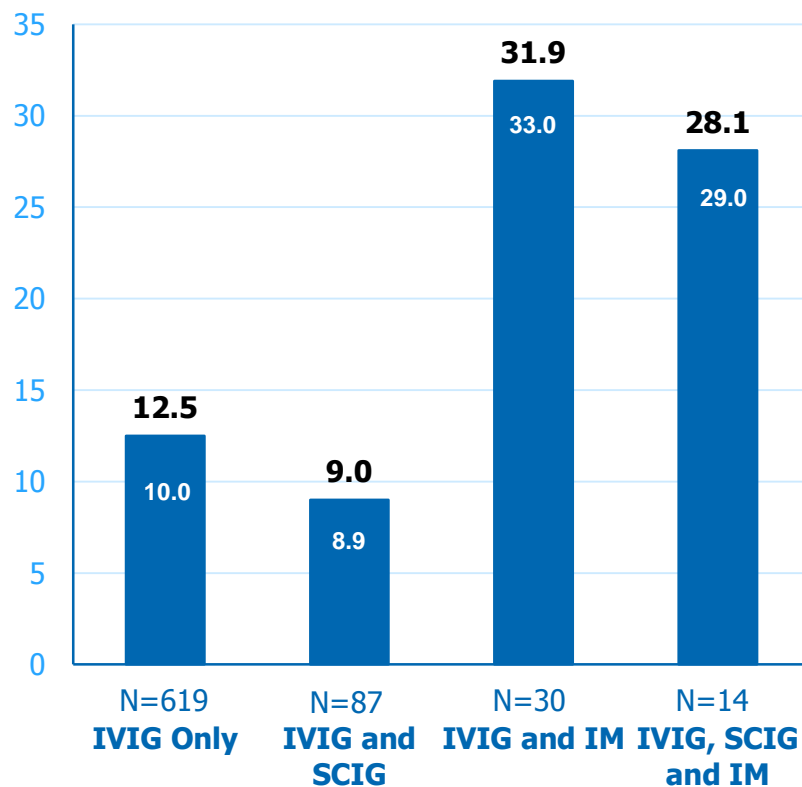


Q19a. Has the patient EVER been treated with intravenous immunoglobulin (IVIG), subcutaneous immunoglobulin (SCIG) therapy or intramuscular (IM) immunoglobulin therapy on a regular basis? SELECT ALL THAT APPLY
Base: Patients who currently use IVIG or SCIG

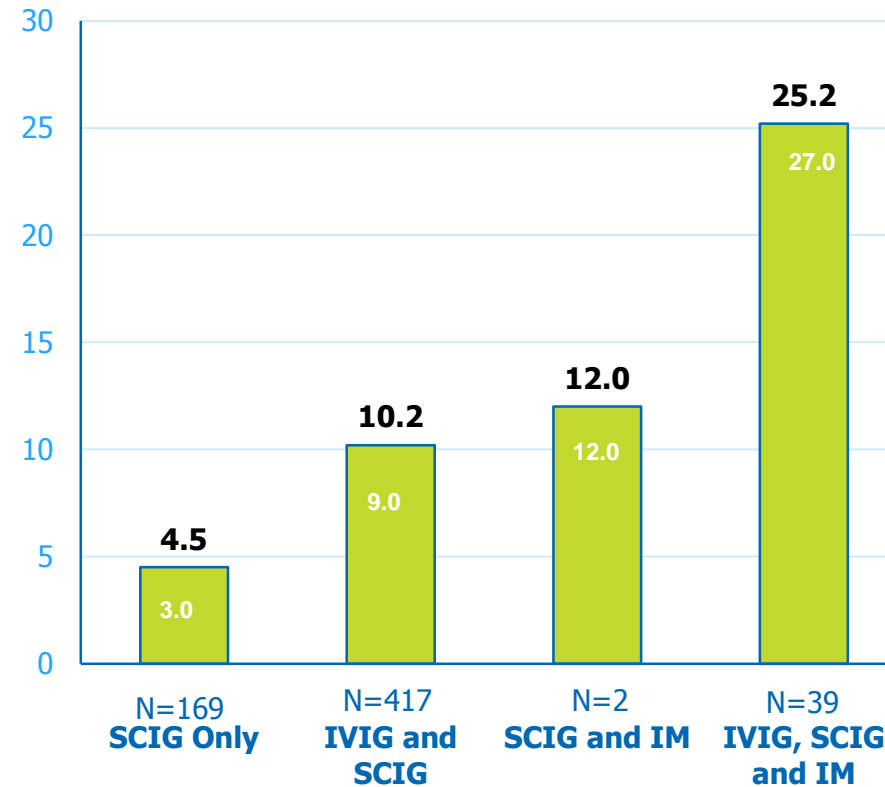


Average Years on Ig Therapy by All Ig Therapies Ever Used

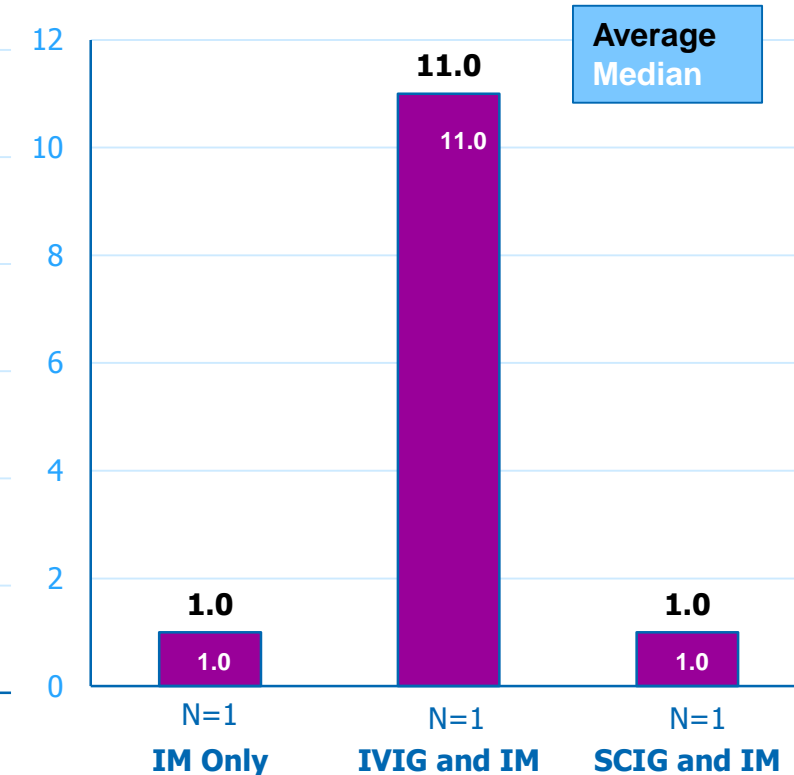
Currently on IVIG



Currently on SCIG



Currently on IM



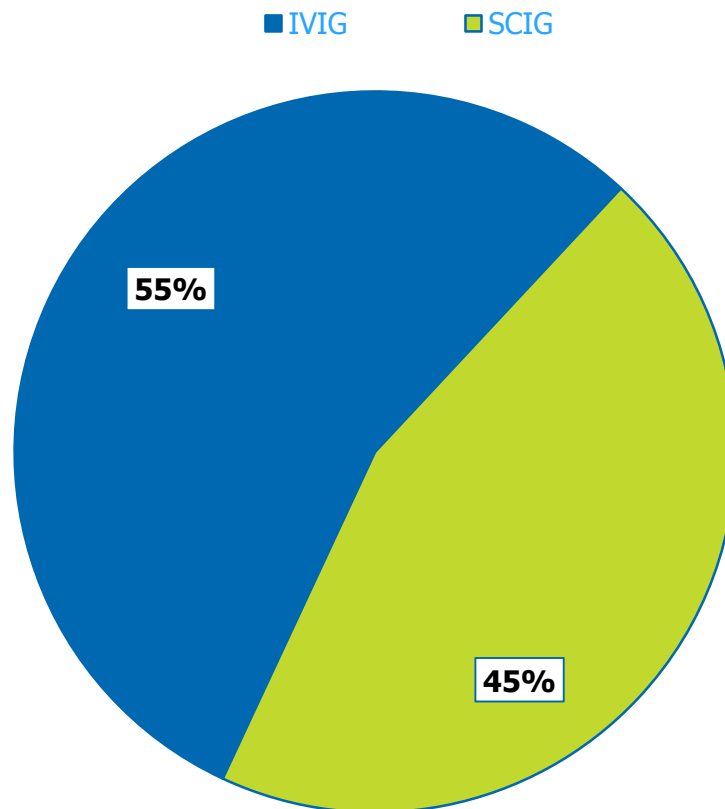
Q19a. Has the patient EVER been treated with intravenous immunoglobulin (IVIG), subcutaneous immunoglobulin (SCIG) therapy or intramuscular (IM) immunoglobulin therapy on a regular basis? SELECT ALL THAT APPLY

Q20. How many years, in total, has he/she been treated for immunodeficiency (Ig therapy) on a regular basis?

Base: Patients who currently use IVIG, SCIG or IM

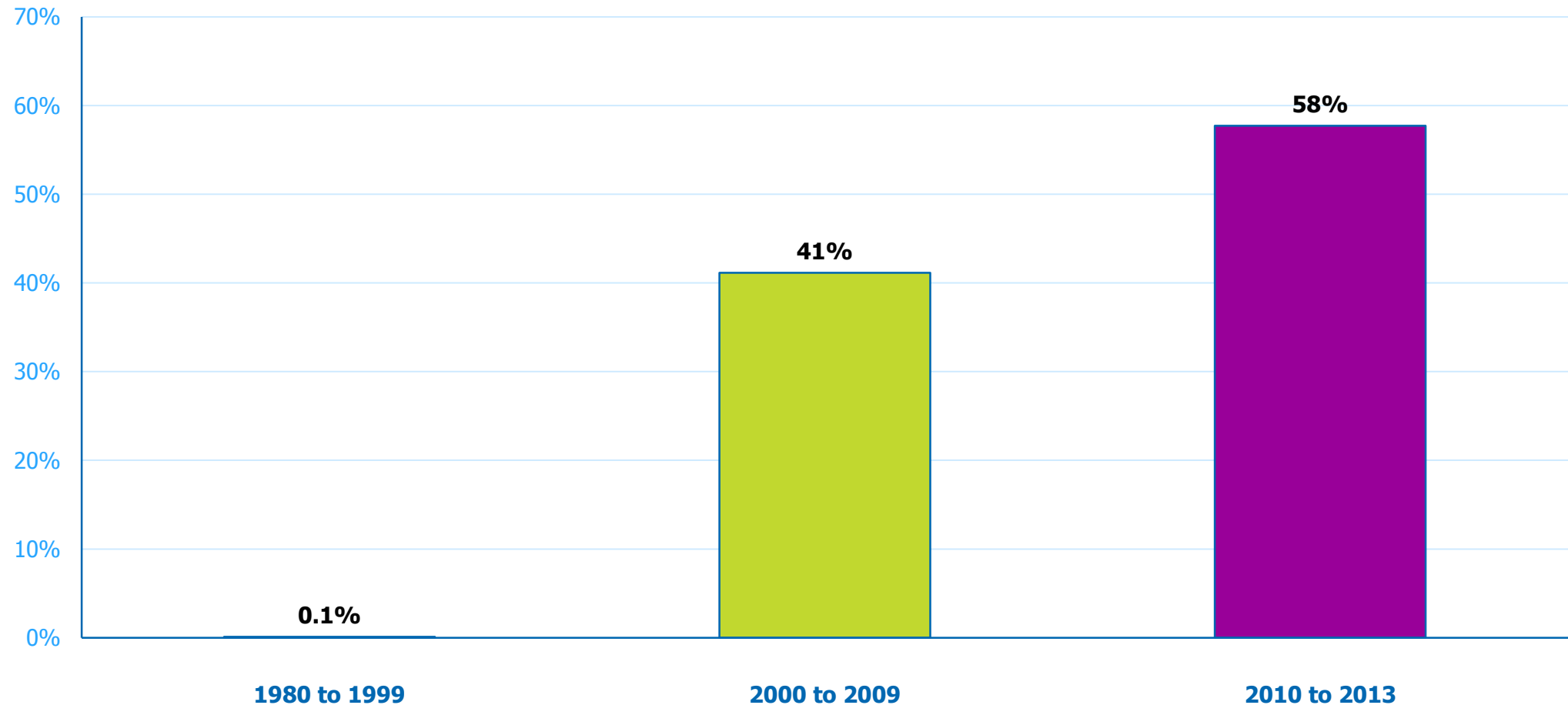


Type of Ig Therapy Currently Used



Q21a. Is he/she currently being treated with SCIG, IVIG or IM for his/her immunodeficiency disease? N=1,425
Base: Patients who currently use IVIG or SCIG

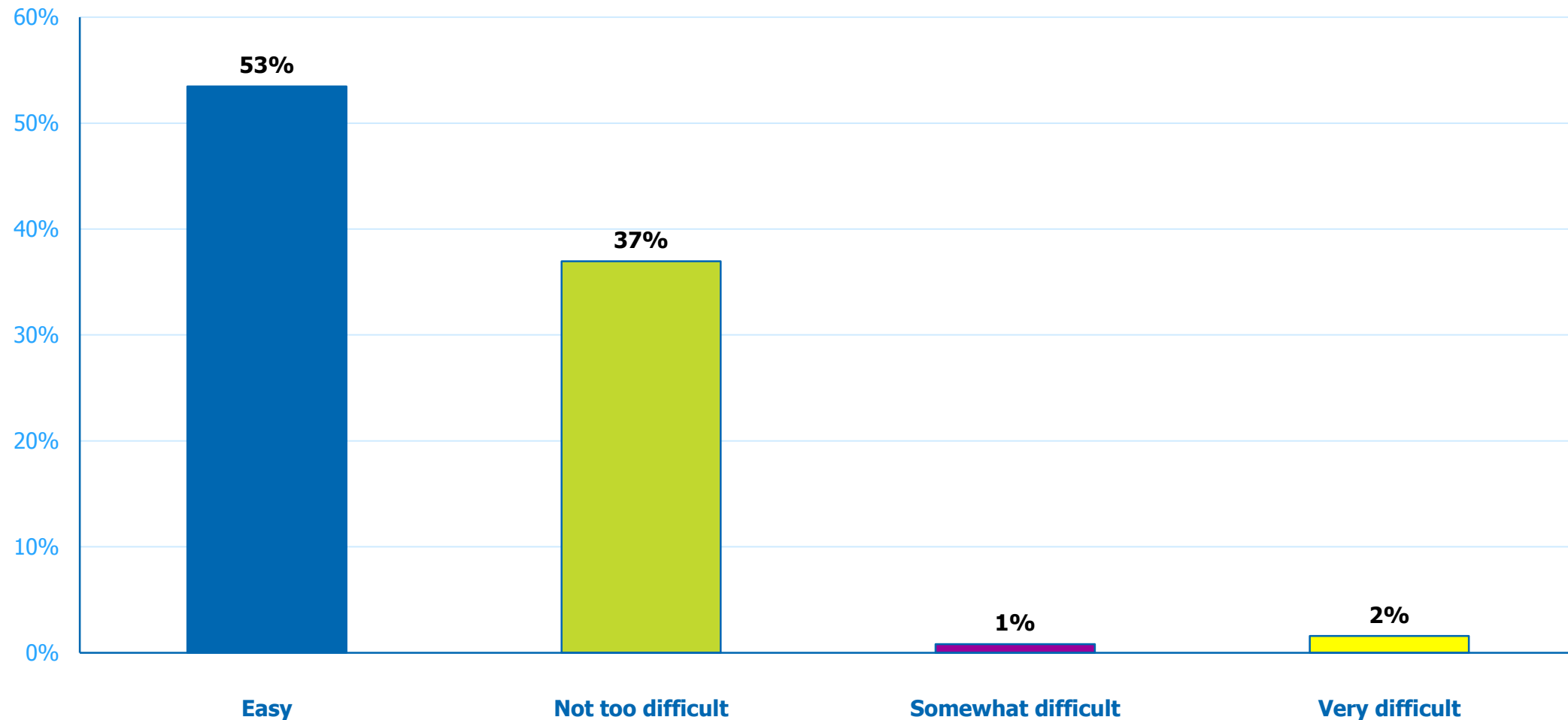
Year Started Using SCIG Therapy



Q22. What year did you start SCIG? N=622
Base: Patients who currently use SCIG



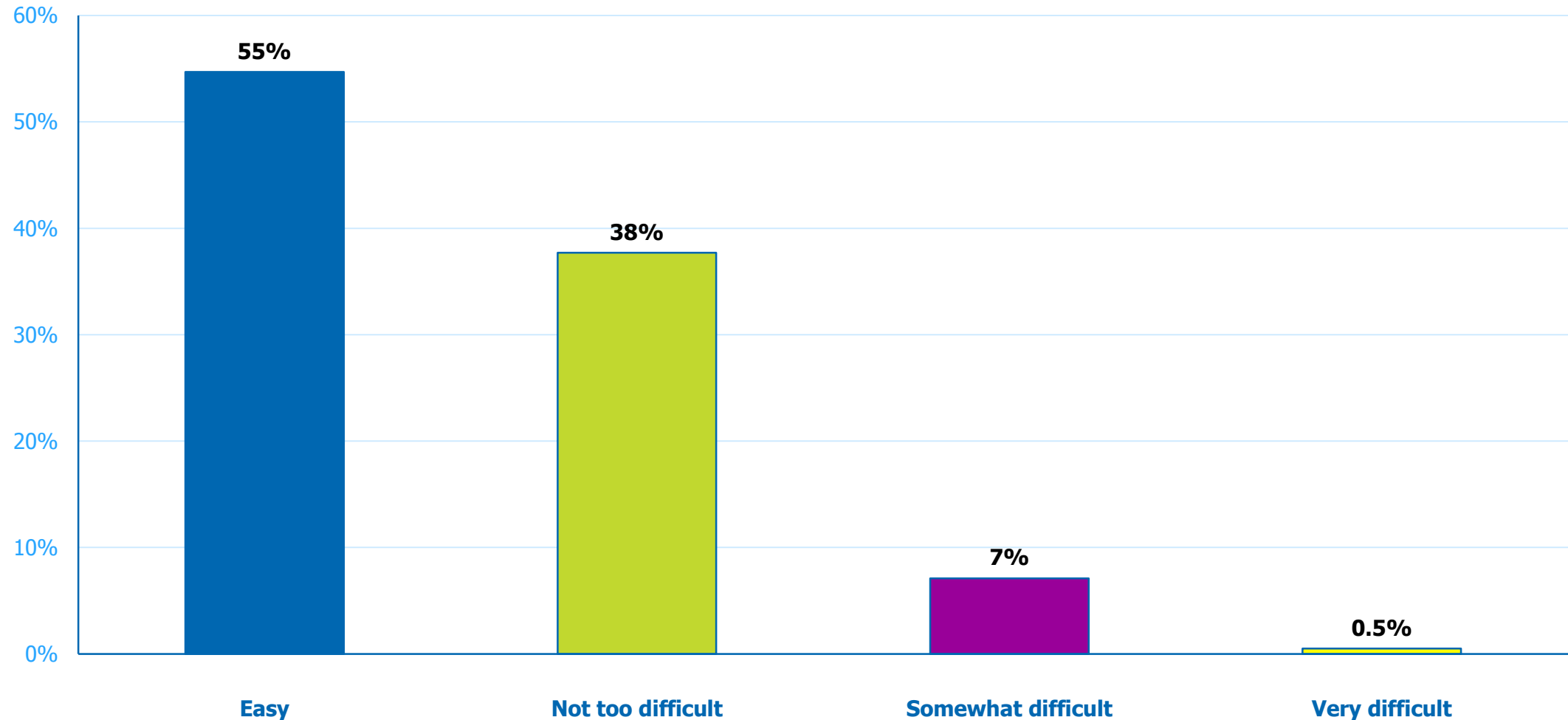
Difficulty Learning to Administer SCIG



Q23a. How difficult was it learning to administer SCIG? N=636
Base: Patients who currently use SCIG



Difficulty Administering SCIG

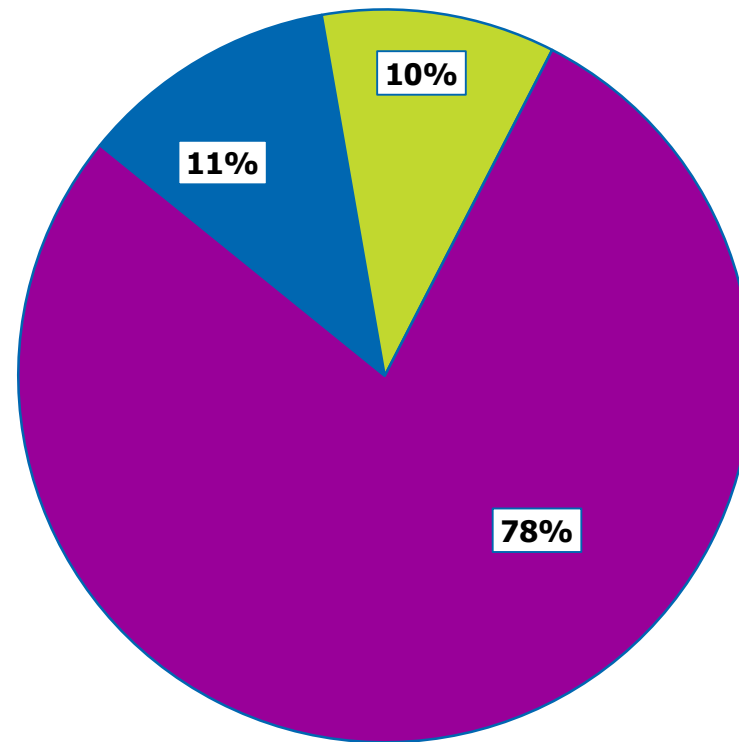


Q23a. How difficult is it to administer SCIG? N=634
Base: Patients who currently use SCIG



Last Time HCP Evaluated SCIG Technique

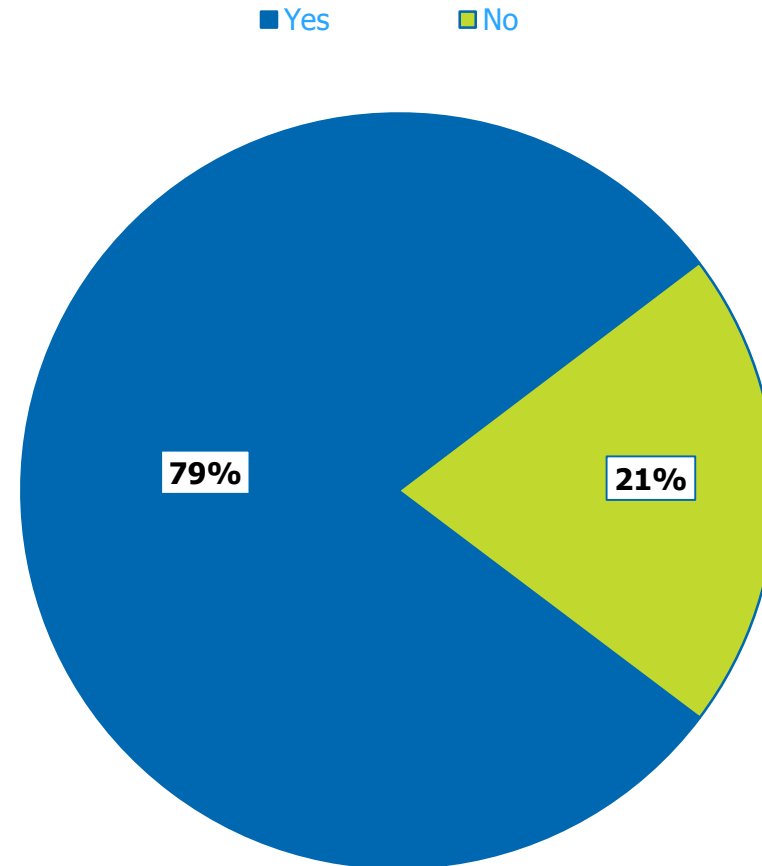
■ Less than six months ■ 6-12 months ■ 1 year or longer



Q24. When was the last time a health professional, such as a nurse or doctor, observed and evaluated the patient's SCIG infusion technique? N=629
Base: Patients who currently use SCIG



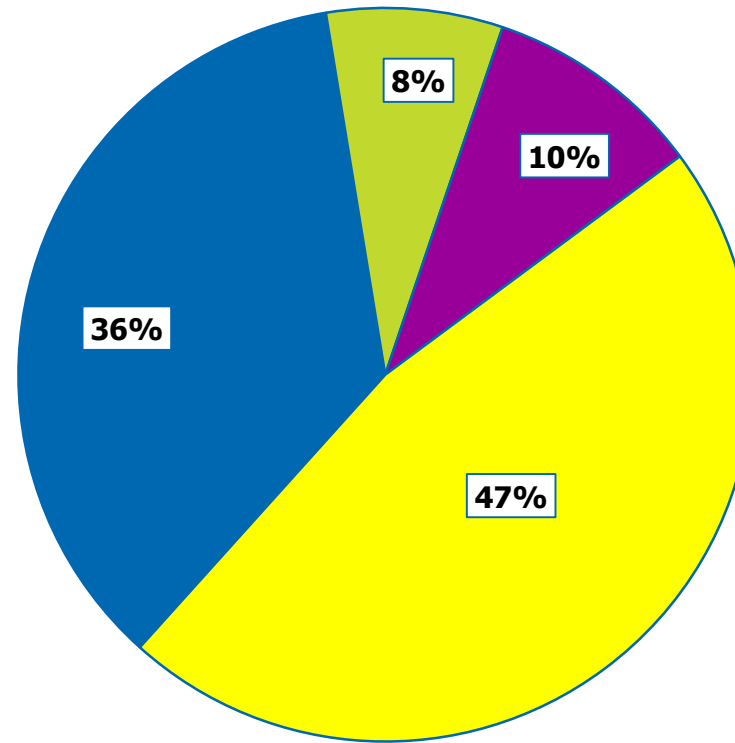
IVIG Prior to SCIG



Q26. Prior to SCIG therapy did the patient receive IVIG therapy? N=636
Base: Patients who currently use SCIG

Switched Products

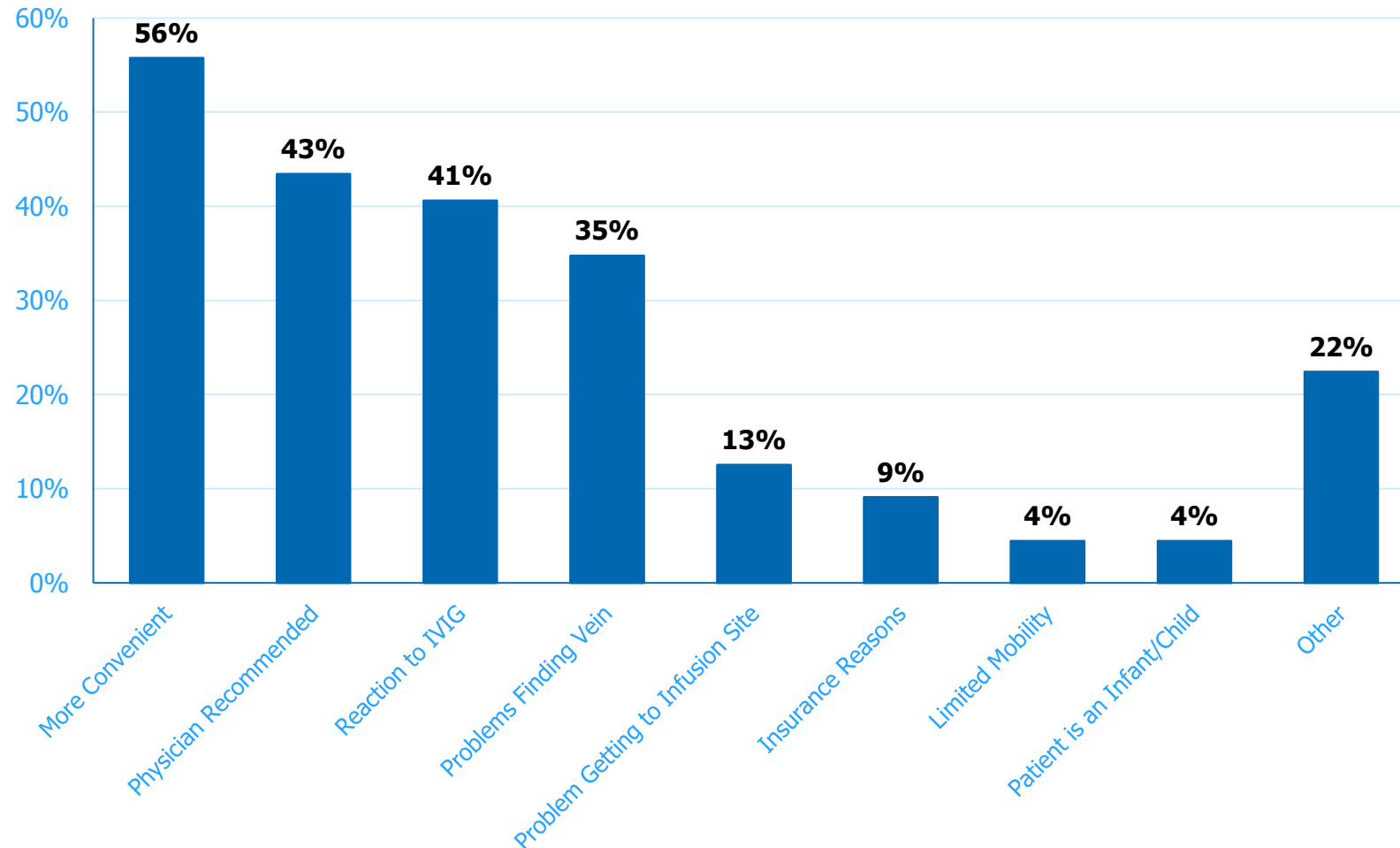
■ Switched from IVIG to SCIG ■ Switched from SCIG to IVIG ■ Only Used SCIG ■ Only Used IVIG



Has the patient switched Ig products? N=1,273
Base: Patients who currently use IVIG, SCIG



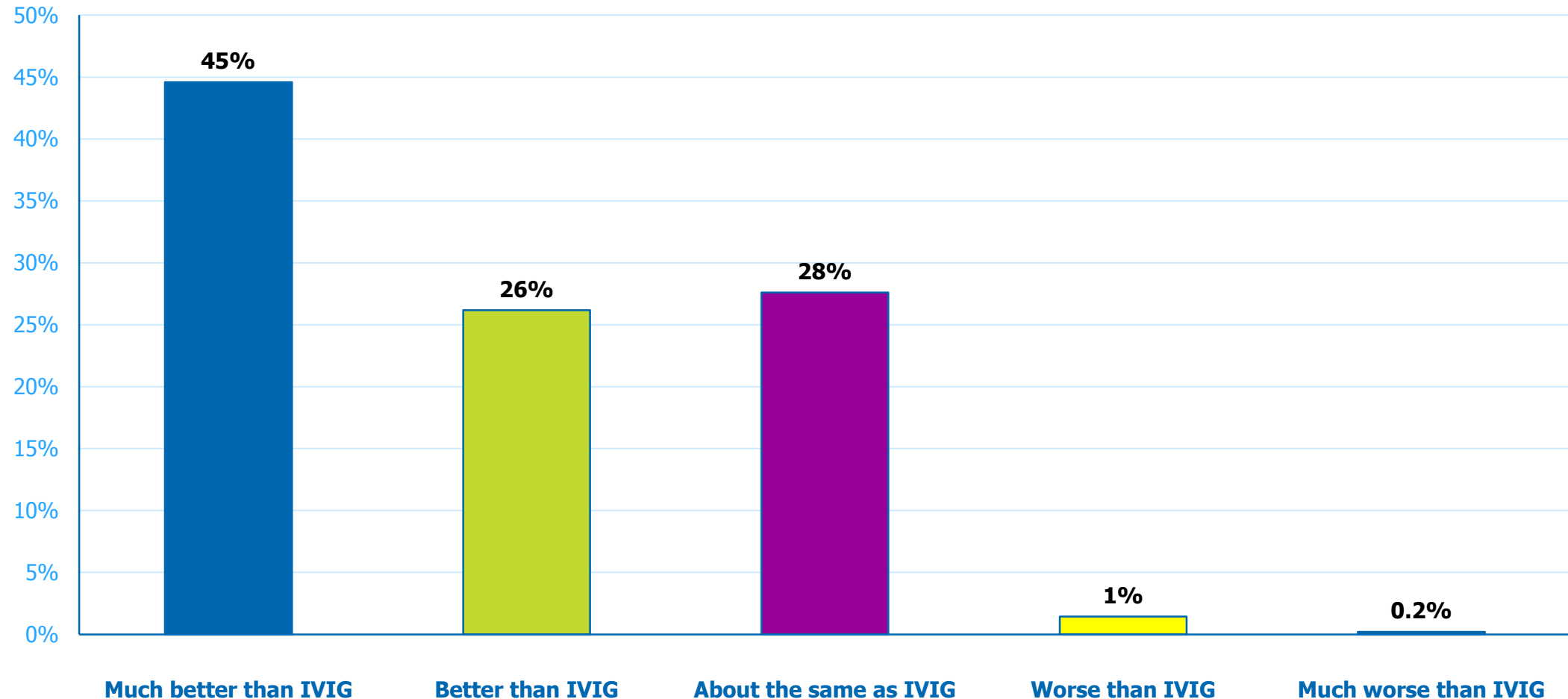
Why Did the Patient Switch from IVIG to SCIG



Q27. Why did the patient switch from IVIG to SCIG? SELECT ALL THAT APPLY N=495
Base: Patients who received IVIG before using SCIG



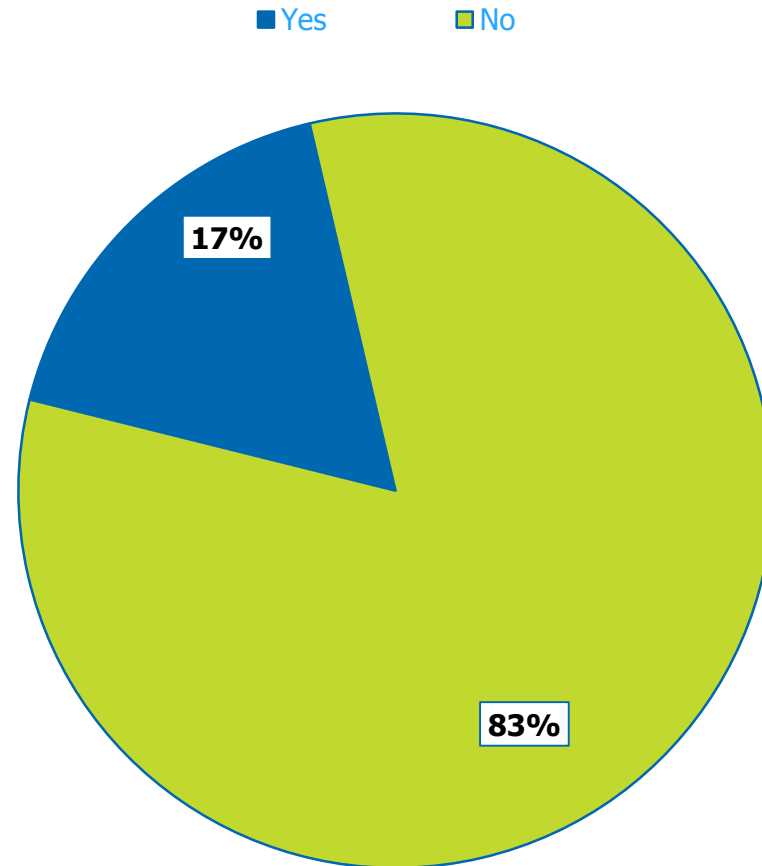
Perceived SCIG Effectiveness



Q28. Compared to IVIG therapy how well do you feel SCIG therapy controls the patient's PI? N=489
Base: Patients who received IVIG before using SCIG

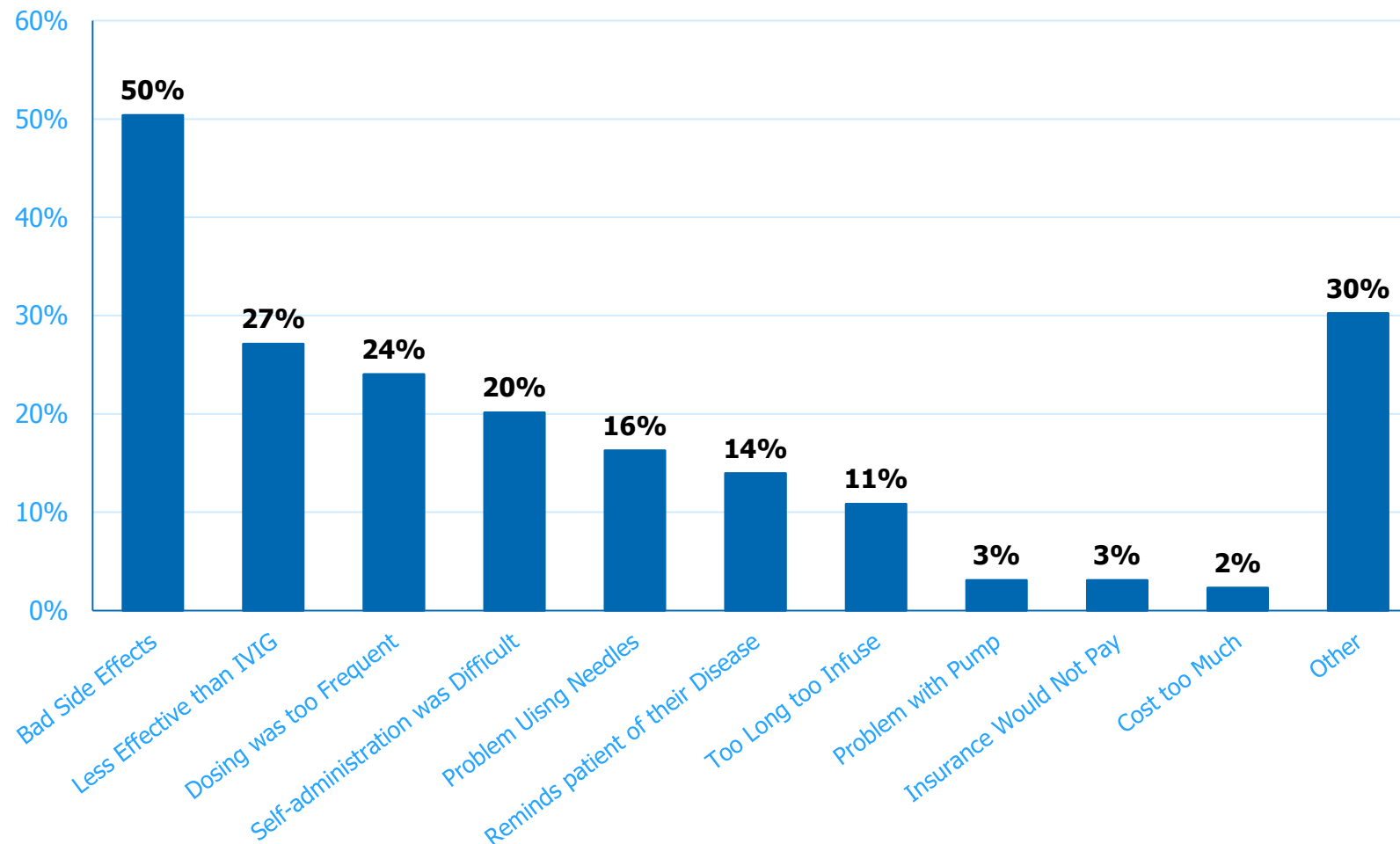


Patient EVER Used SCIG



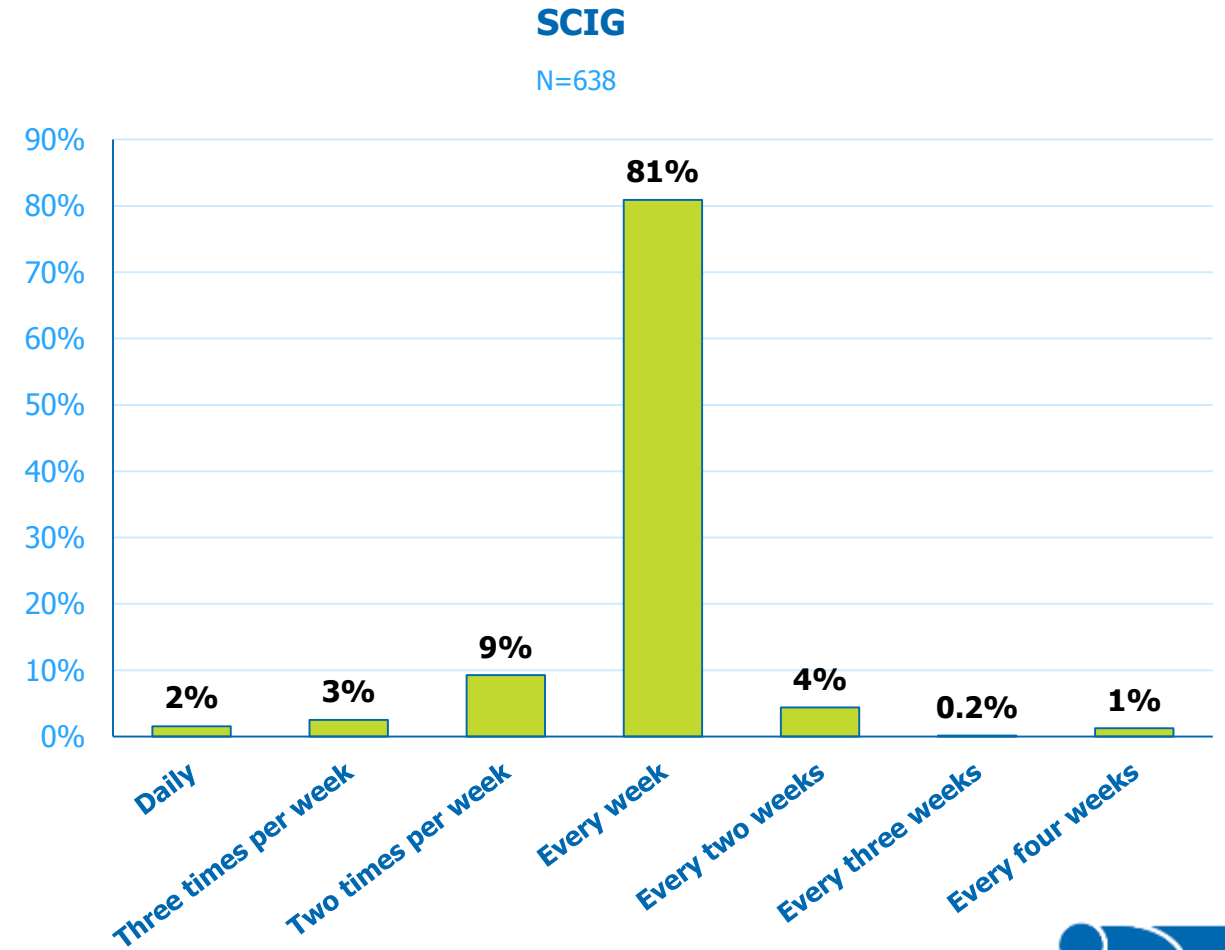
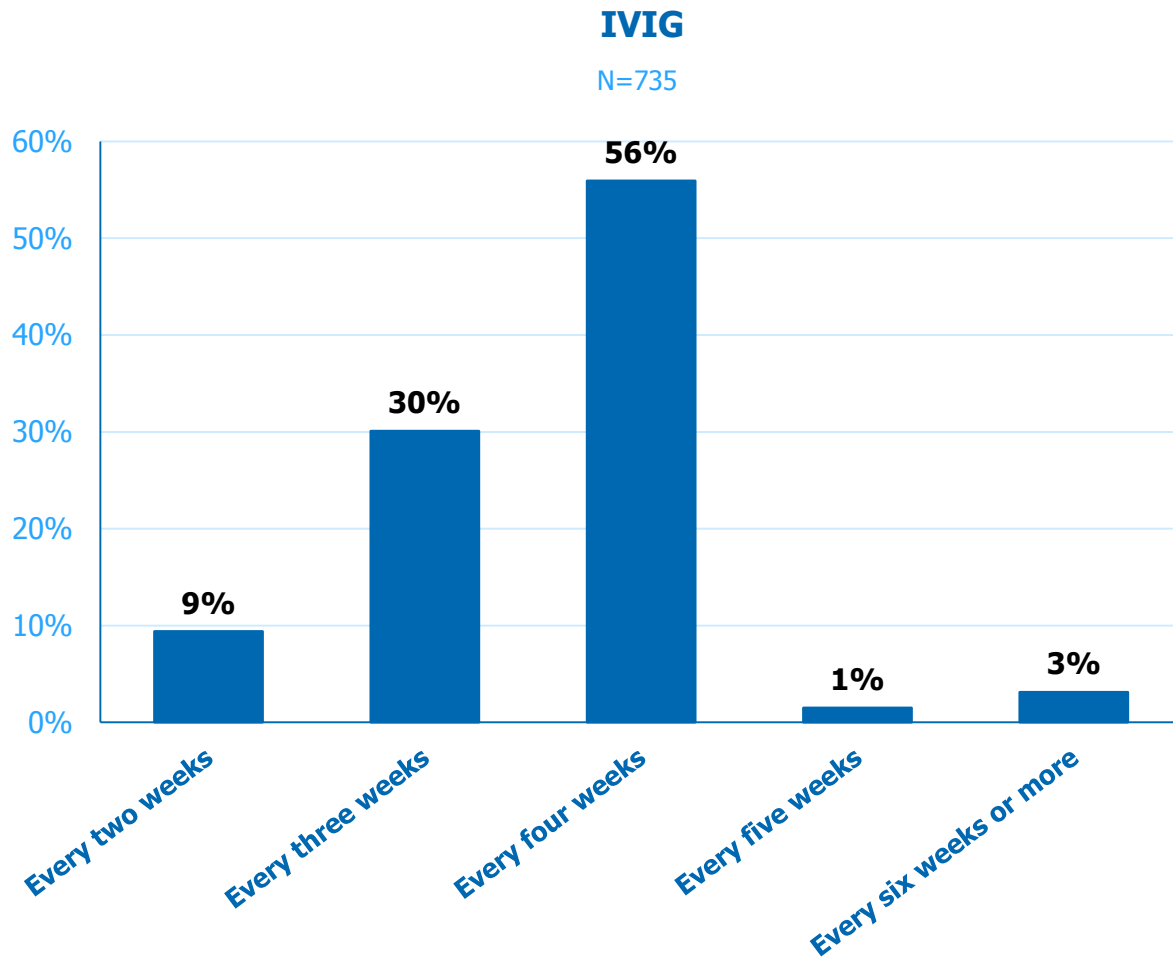
Q29a. Has the patient ever been on SCIG therapy? N=762
Base: Patients who currently use IVIG or IM

No Longer Using SCIG



Q29b. Did the patient experience any of the following infections during the 12 months prior to diagnosis? N=129
Base: Patients who currently use IVIG or IM that also used SCIG

Frequency of Ig Treatment*



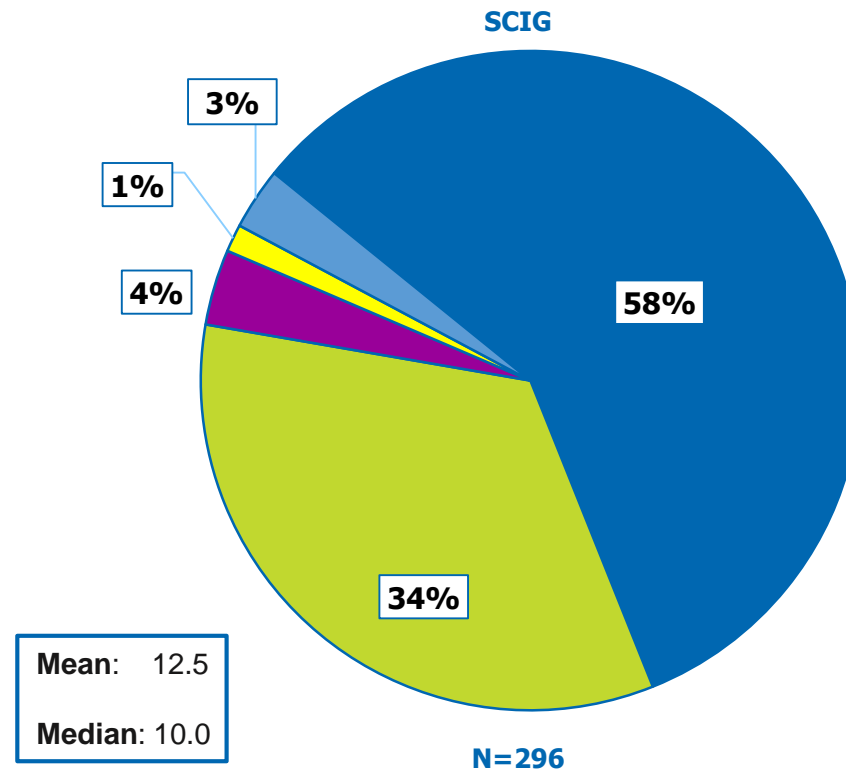
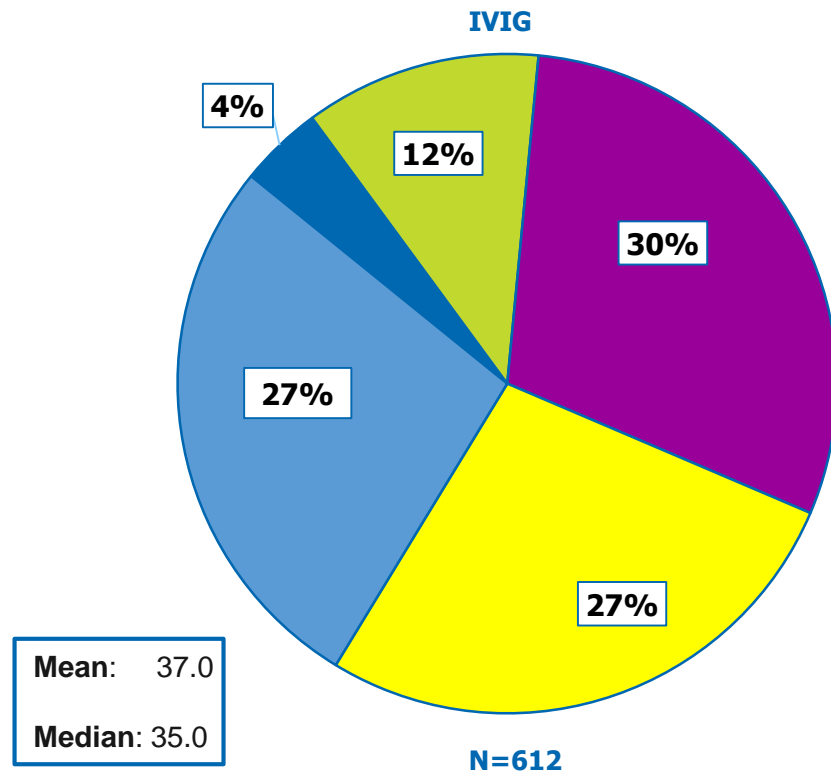
* p<.001

Q30. On average, how often does he/she get their IVIG or SCIG therapy?
Base: Patients who currently use IVIG or SCIG



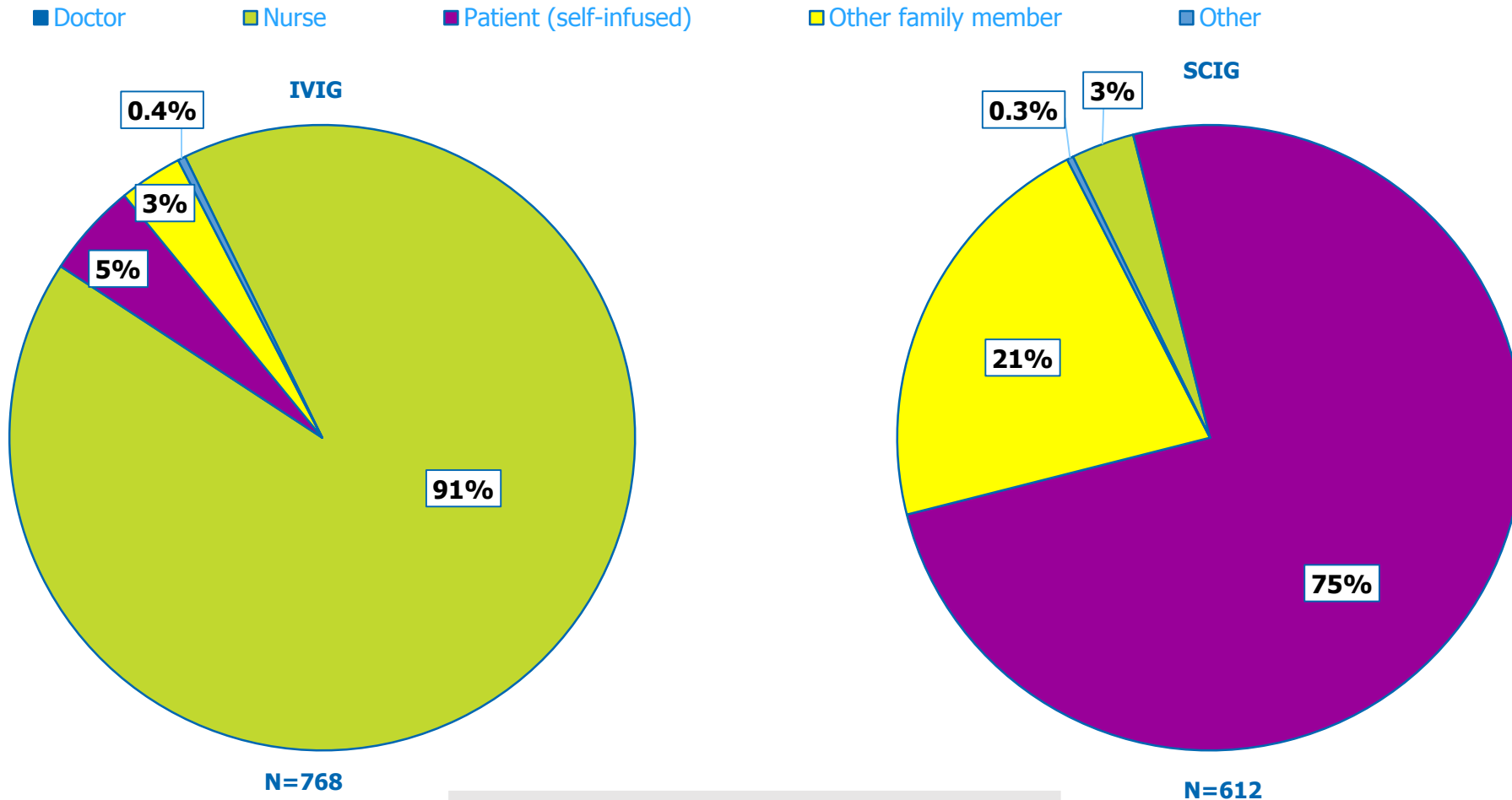
Grams of Ig per Infusion for Adult Patients

■ 1 to 10 grams ■ 11 to 20 grams ■ 21 to 30 grams ■ 31 to 40 grams ■ More than 40 grams



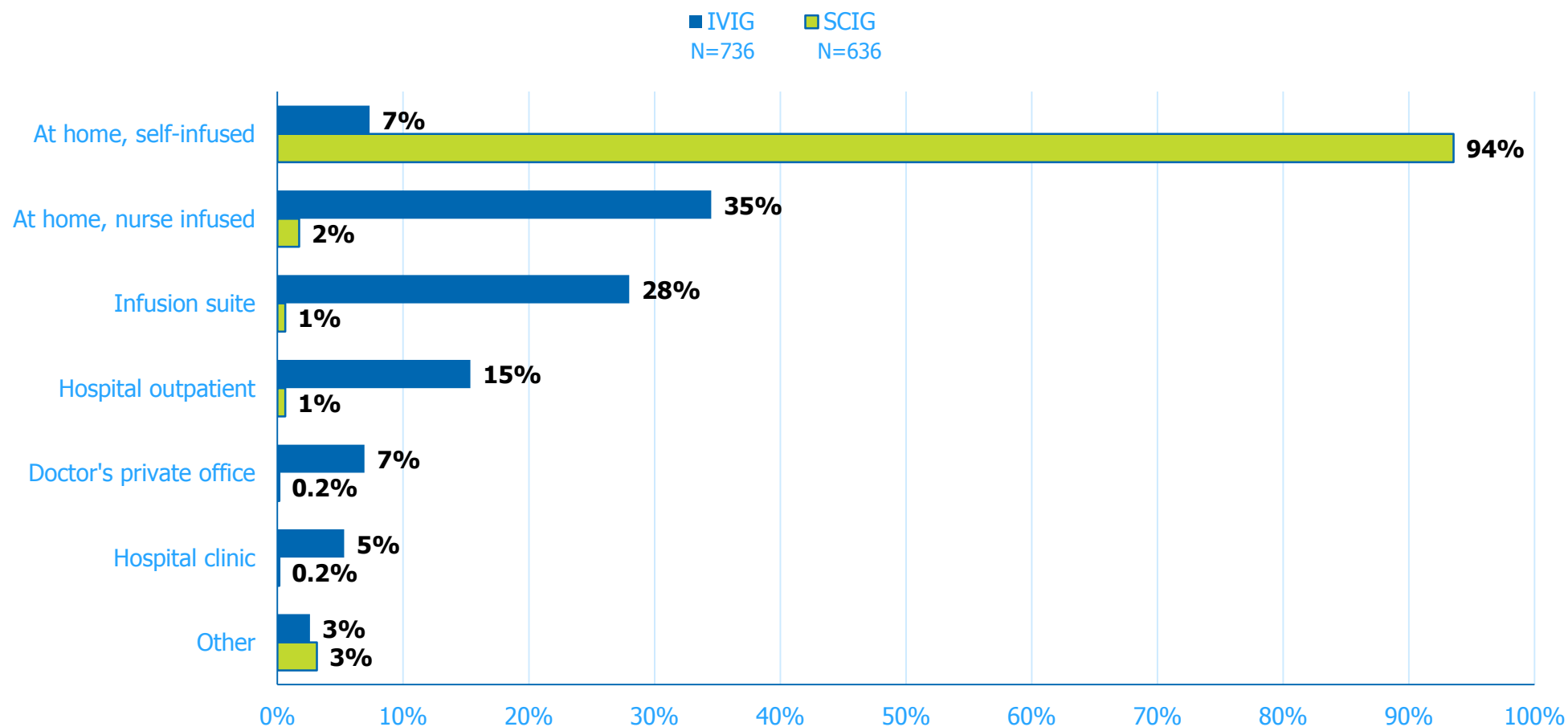
Q31. About how many grams of Ig per infusion does he/she normally receive?
Base: Adult Patients who currently use IVIG or SCIG

Who Administers Ig Therapy



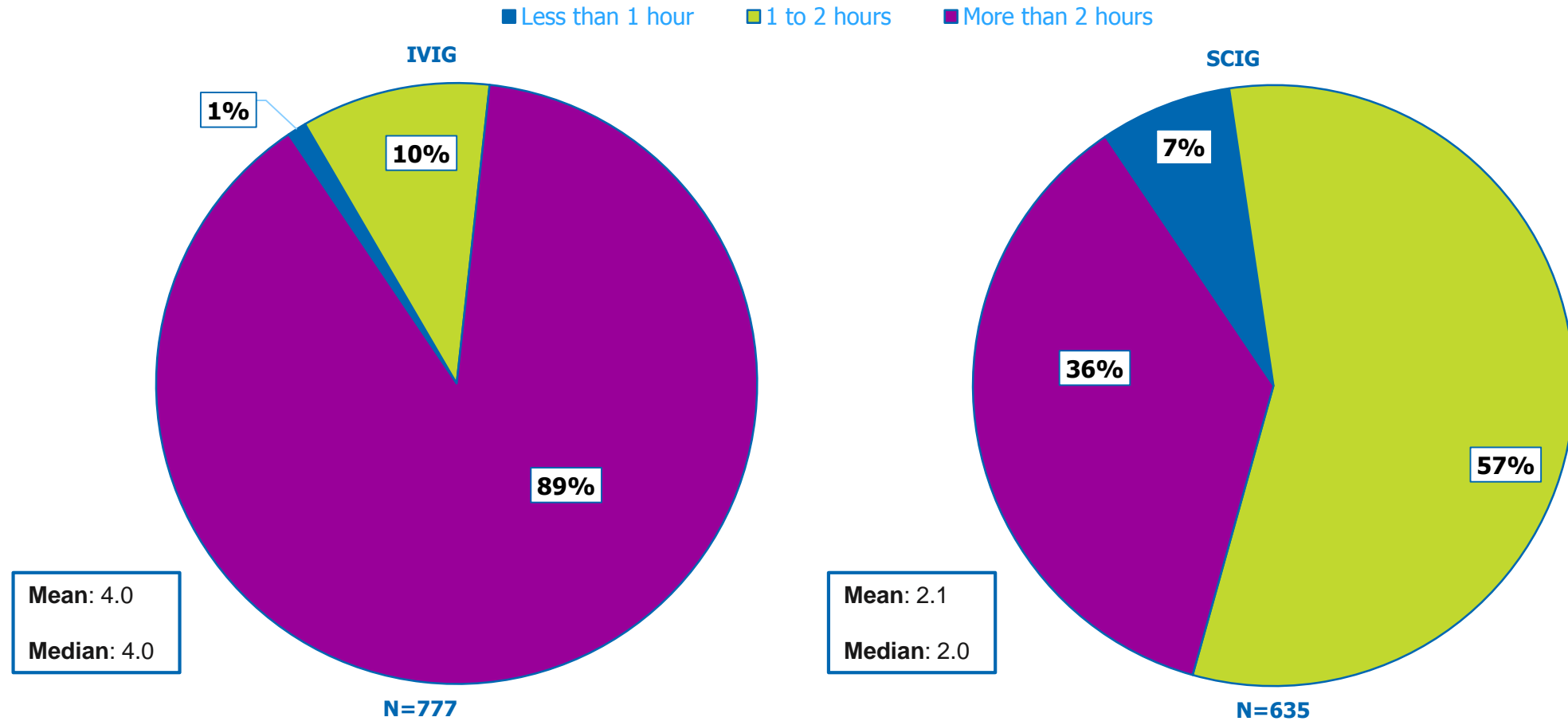
Q32. Who usually administers the therapy?
Base: Patients who currently use IVIG or SCIG

Where is Ig Therapy Administered



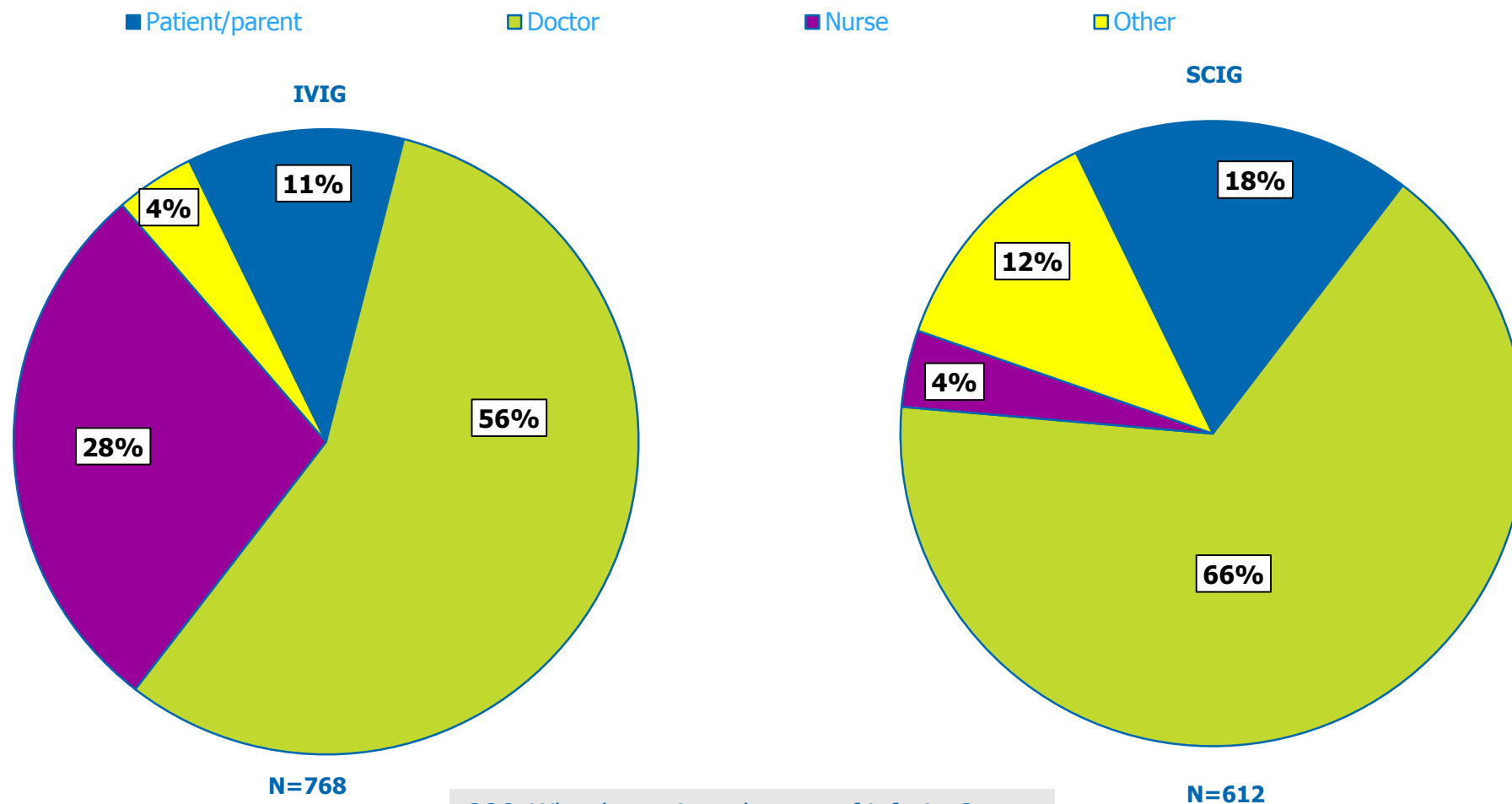
Q33. Where does the patient usually receive his/her Ig therapy?
Base: Patients who currently use IVIG or SCIG

Total Time to Complete Ig Therapy



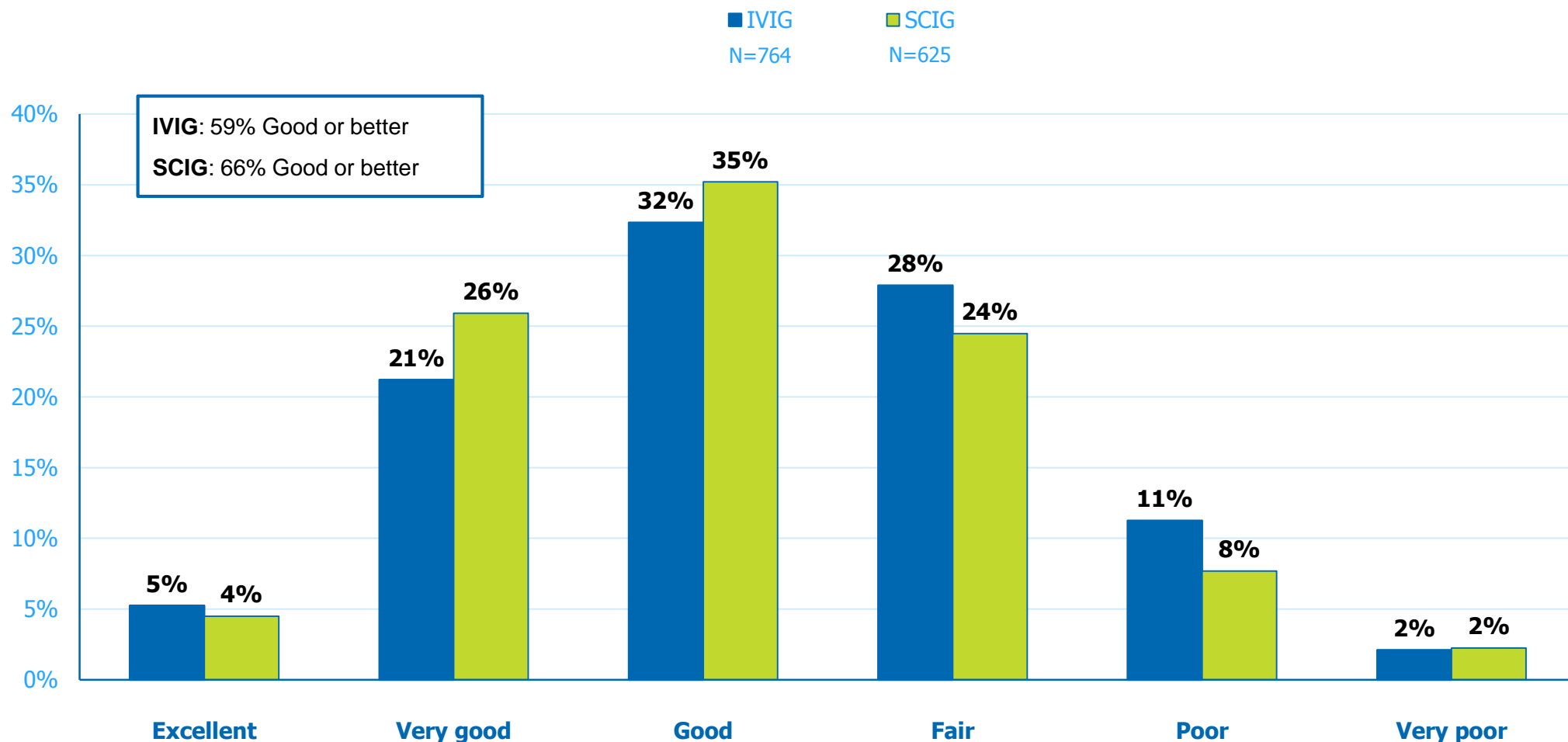
Q34. How long does the therapy usually take?
Base: Patients who currently use IVIG or SCIG

Who Determines the Rate of Infusion



Q36. Who determines the rate of infusion?
Base: Patients who currently use IVIG or SCIG

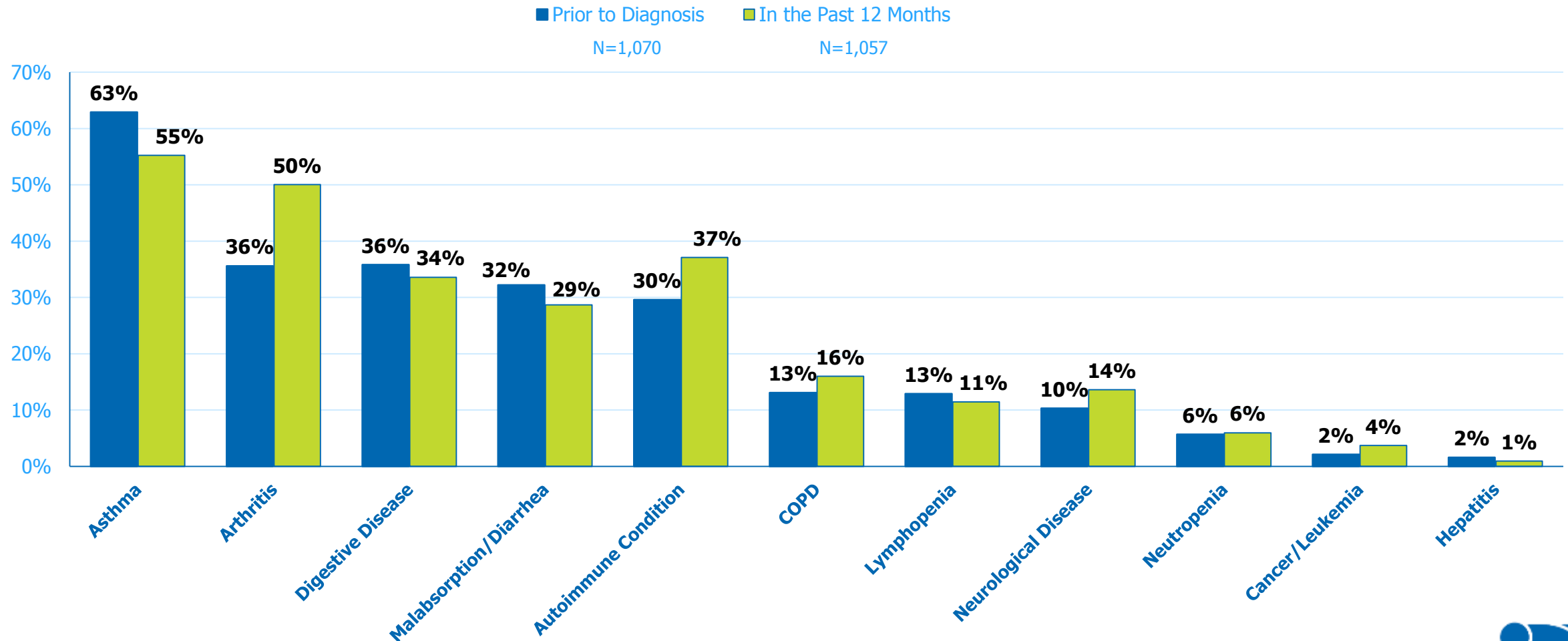
Currently: Patient's General Health IVIG vs. SCIG



Q52. In general would you say the patient's health is...
Base: Patients who currently use IVIG or SCIG



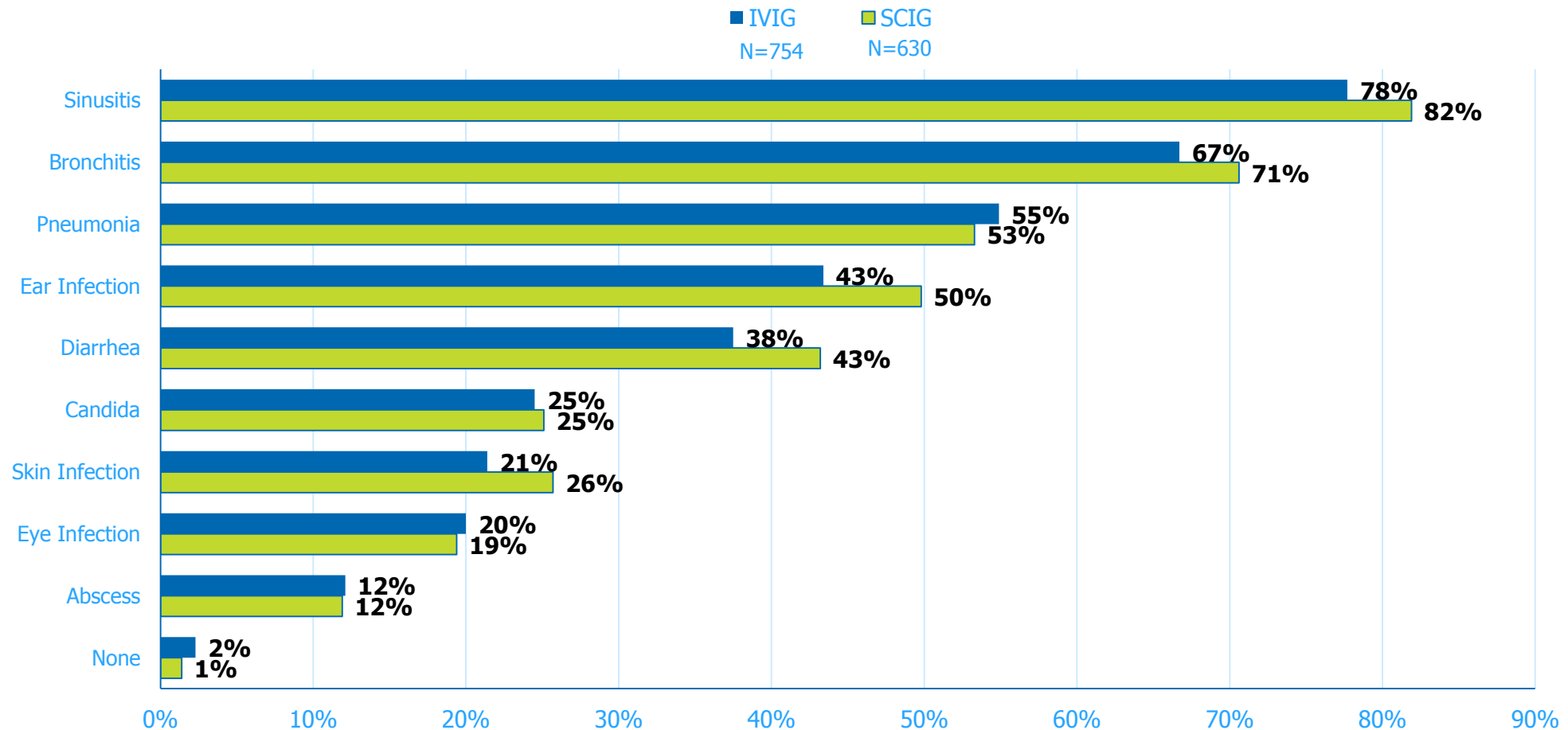
Other Chronic Conditions



Q10. During the 12 months prior to diagnosis, did he/she have ... ? SELECT ALL THAT APPLY
Q53. During the PAST 12 MONTHS, has he/she had...
Base: Patients who currently use IVIG or SCIG



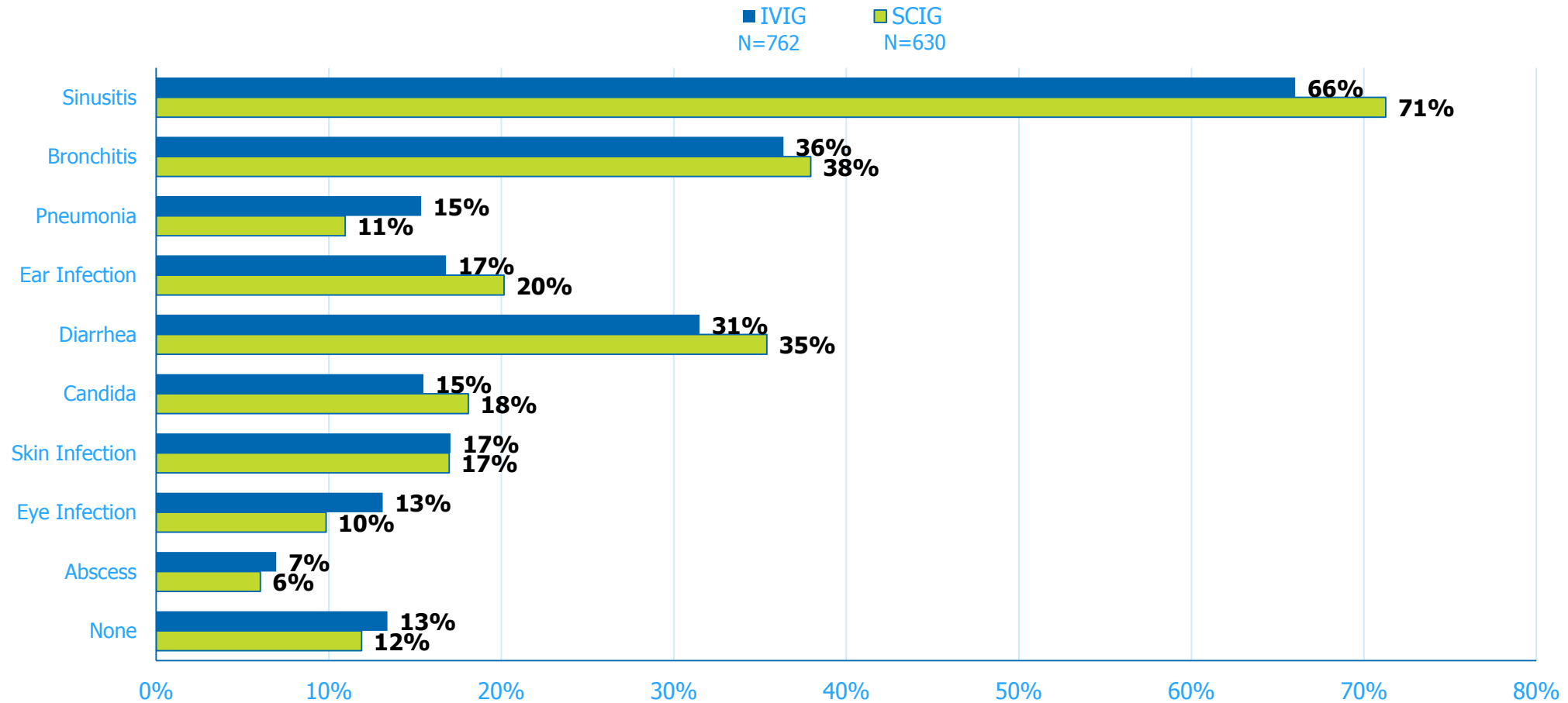
Infections Prior to Diagnosis IVIG vs. SCIG



Q11. Did the patient experience any of the following infections during the 12 months prior to diagnosis?
Base: Patients who currently use IVIG or SCIG



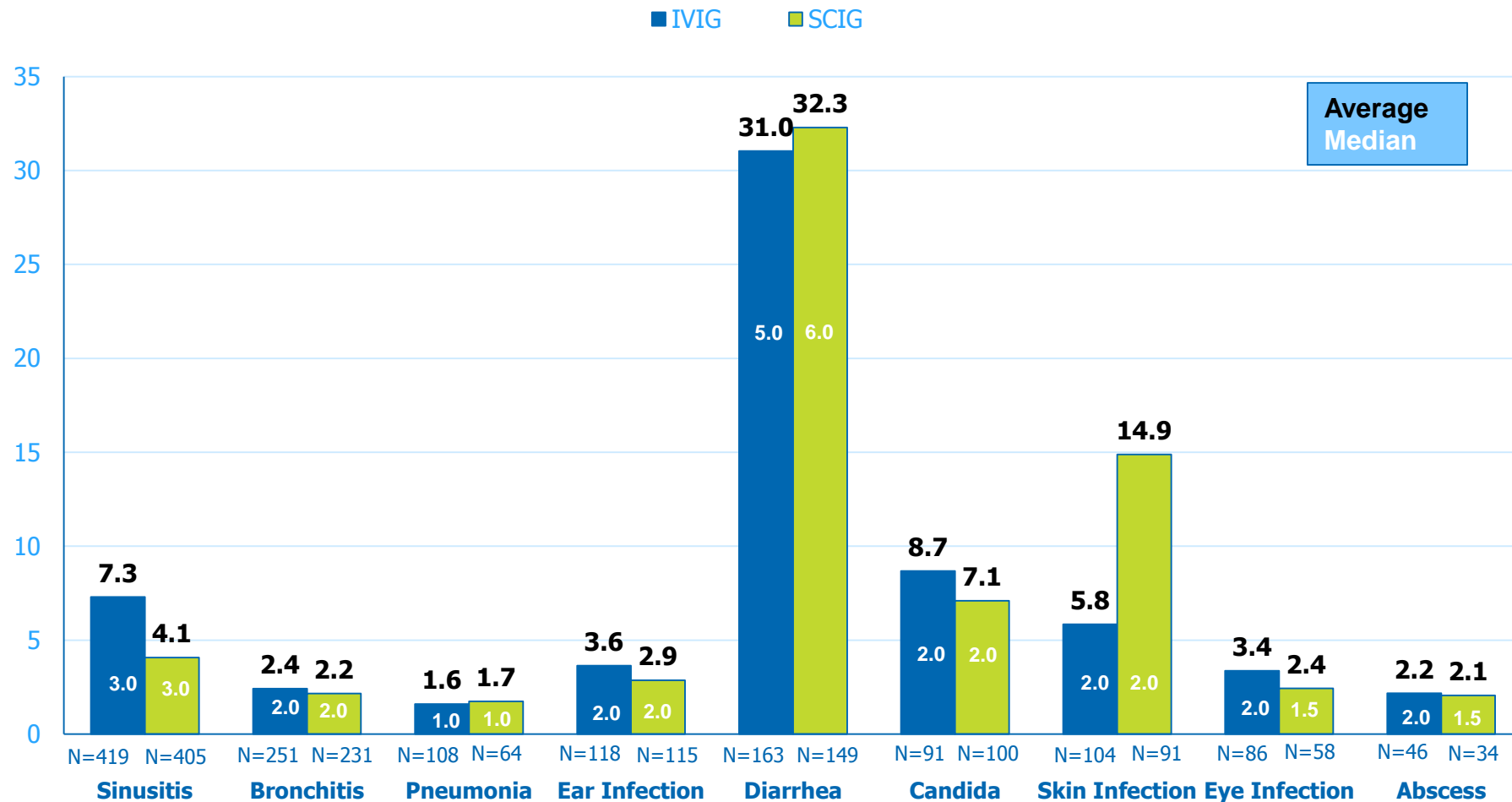
Infections in the Past 12 Months IVIG vs. SCIG



Q54. Did he/she experience the following infections during the PAST 12 MONTHS?
Base: Patients who currently use IVIG or SCIG



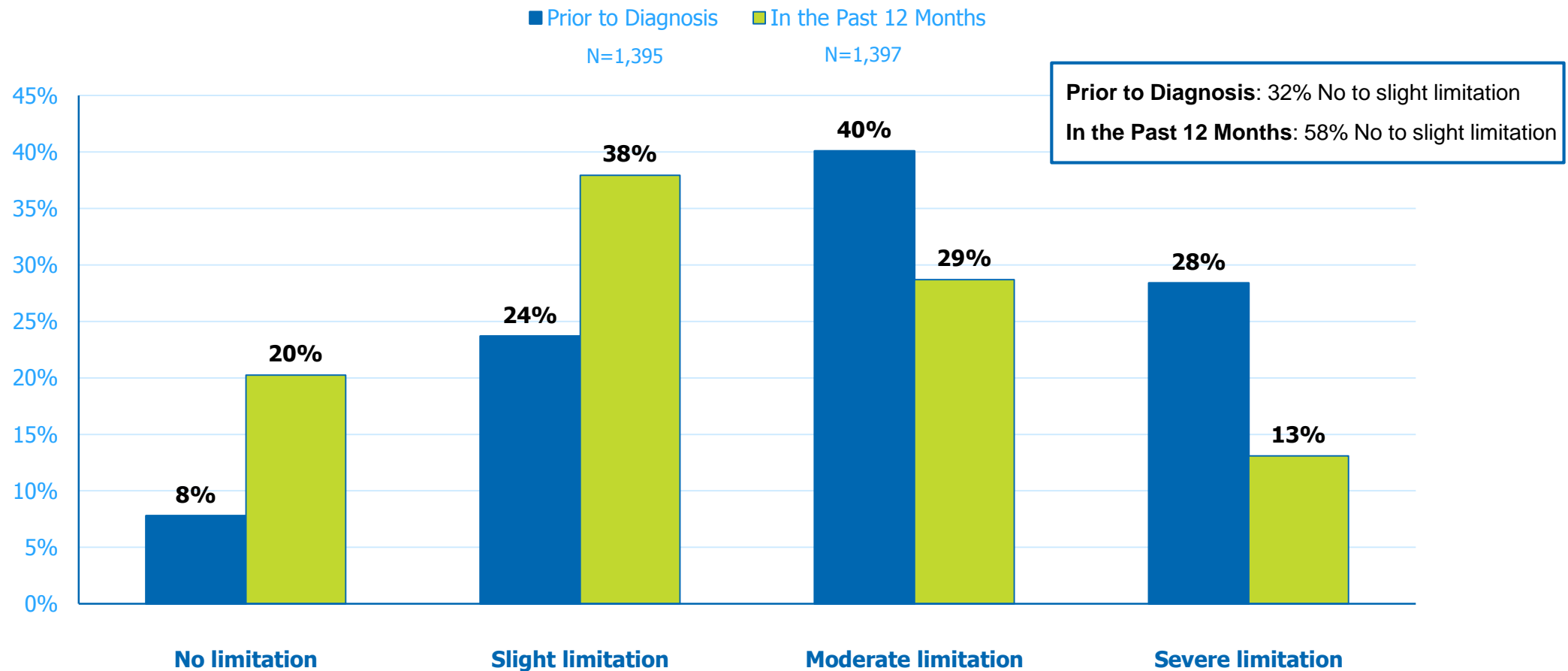
Number of Infections in the Past 12 Months IVIG vs. SCIG



Q54. Did the patient experience any of the following infections during the 12 months prior to diagnosis?
Base: Patients who currently use IVIG or SCIG and reported at least 1 infection



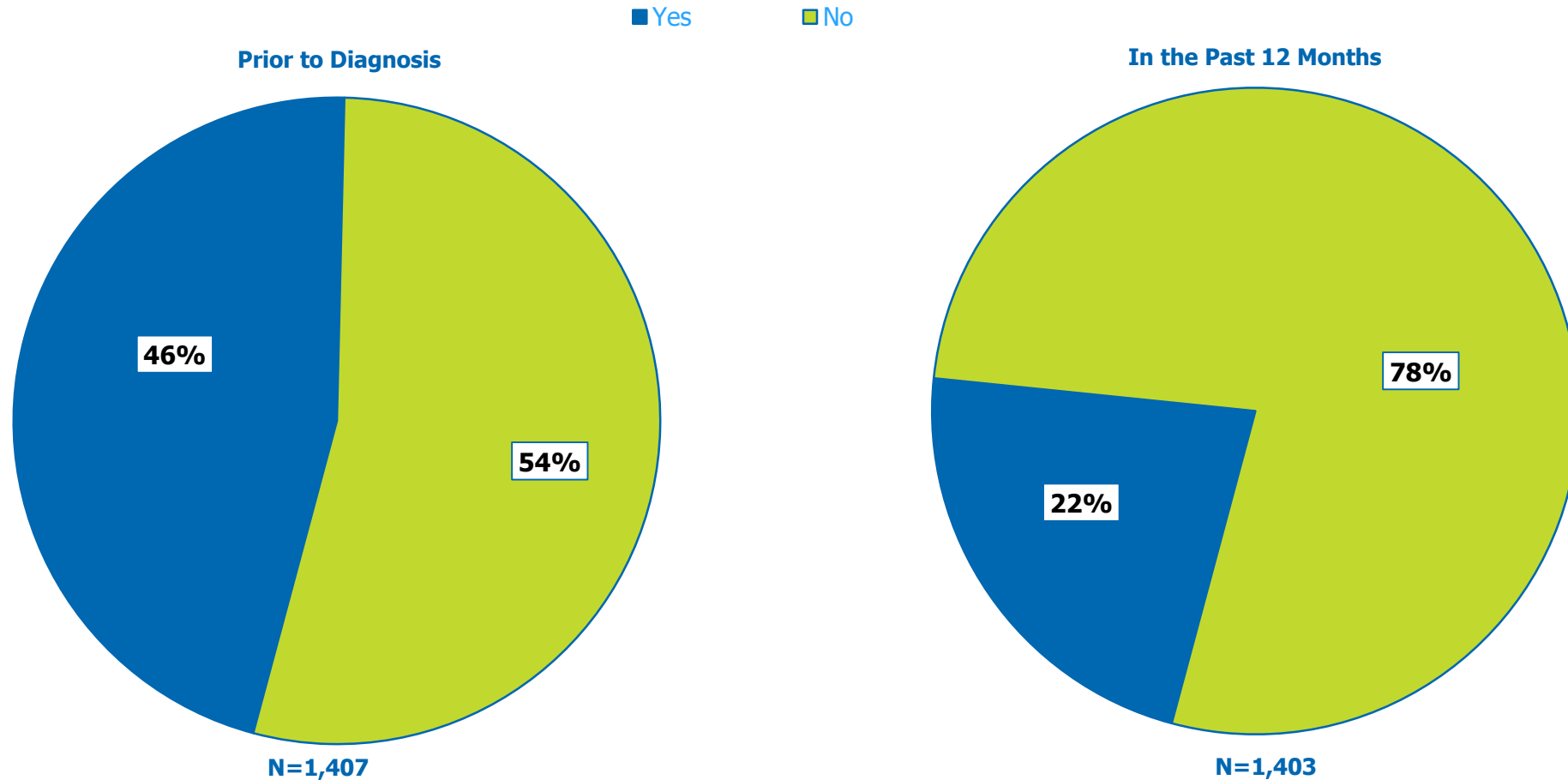
Activity Limitation



Q12. During the 12 months prior to diagnosis, how much was he/she limited in work, play or normal physical activity as a result of his/her health.
Q55. During the PAST 12 MONTHS, how much has he/she been limited in work, play or normal physical activity as a result of his/her health?
Base: Patients who currently use IVIG or SCIG



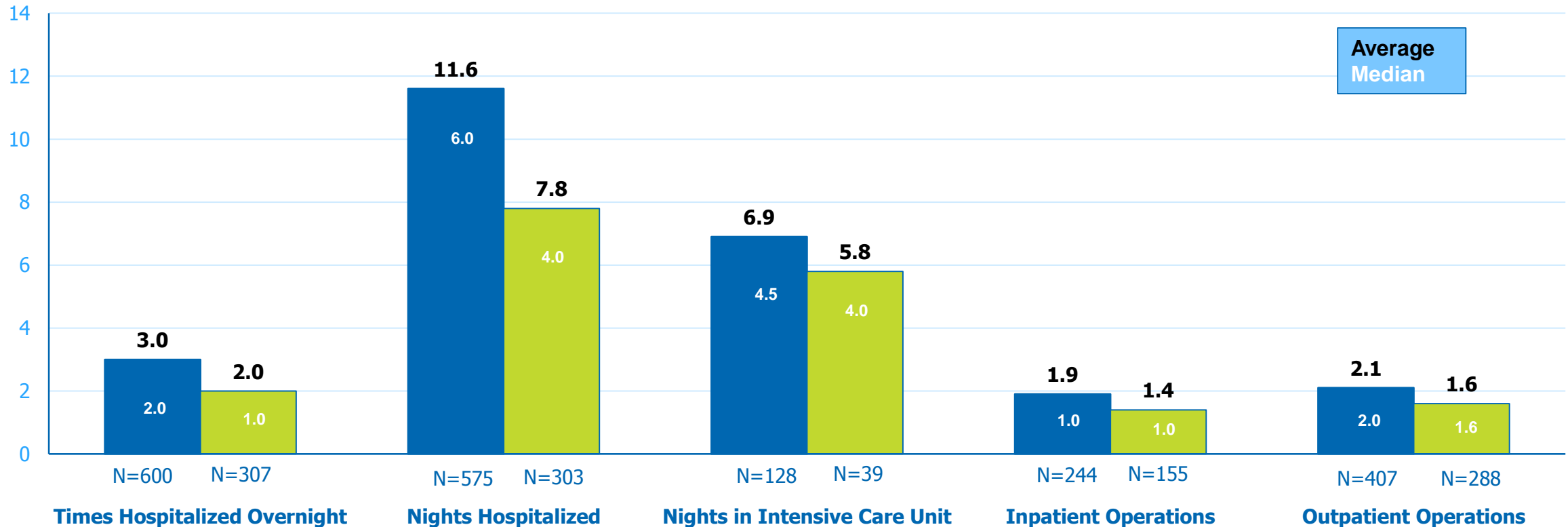
Hospitalized Overnight



Q13a. Was he/she hospitalized overnight or longer for any reason during the 12 months prior to diagnosis?
Q56a. Has he/she been hospitalized overnight or longer for any reason during the past 12 months?
Base: Patients who currently use IVIG or SCIG

Number of Hospitalizations and Operations

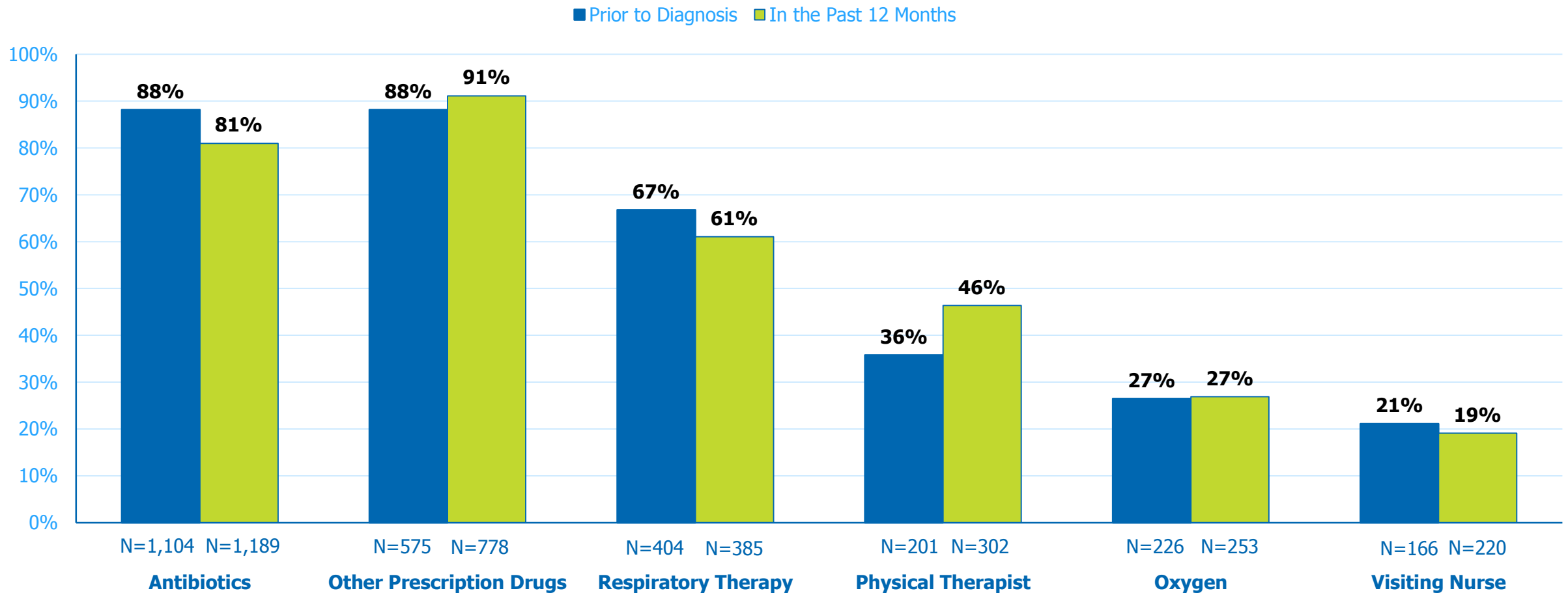
■ Prior to Diagnosis ■ In the Past 12 Months



Q13b. How many TIMES was he/she hospitalized in the 12 months prior to diagnosis?
 Q13c. How many NIGHTS was he/she hospitalized in the 12 months prior to diagnosis?
 Q13d. How many NIGHTS, if any, was he/she in an INTENSIVE CARE UNIT in the 12 months prior to diagnosis?
 Q56b. How many TIMES was he/she hospitalized in the past 12 months?
 Q56c. How many NIGHTS was he/she hospitalized in the past 12 months?
 Q56d. How many NIGHTS, if any, was he/she in an INTENSIVE CARE UNIT in the past 12 months?
 Base: Patients who currently use IVIG or SCIG who experienced an overnight hospitalization
 Q14. How many operations, if any, did he/she have in the 12 months prior to diagnosis?
 Q57. How many operations, if any, did he/she have in the past 12 months?
 Base: Patients who currently use IVIG or SCIG

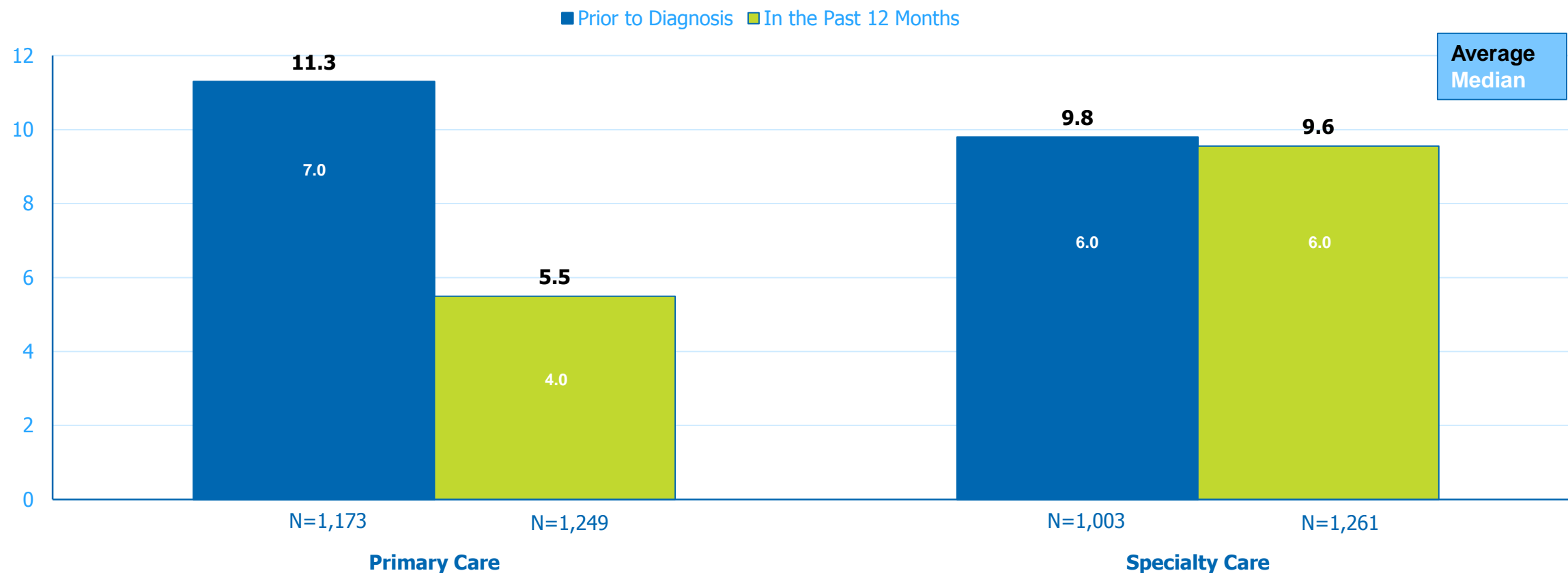


Used for More Than One Week...



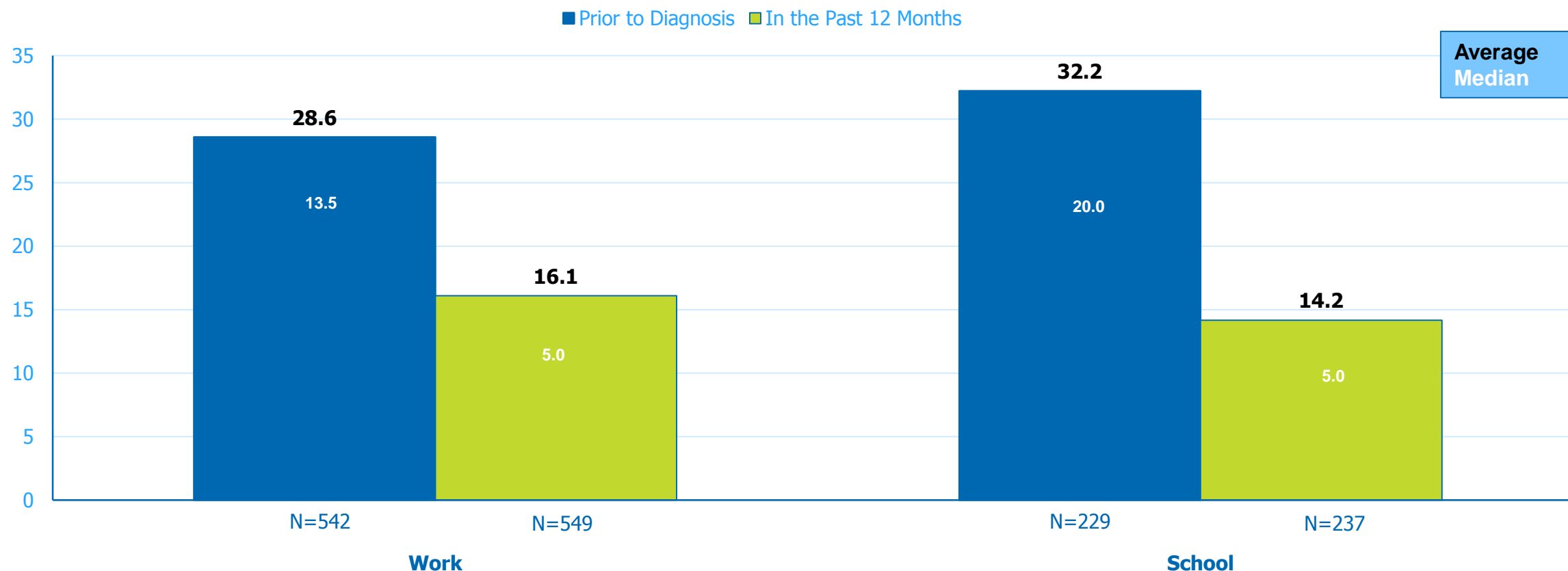
Q15. In the 12 months prior to diagnosis, approximately how many days did he/she use.....
Q58. Approximately how many days in the past 12 months did he/she use.....
Base: Patients who currently use IVIG or SCIG

Doctor Visits



Q16. Not counting hospitalizations, about how many DOCTOR VISITS did the patient make during the 12 months prior to diagnosis?
Q59a. Not counting hospitalizations, about how many doctor visits did the patient make during the past 12 months?
Base: Patients who currently use IVIG or SCIG

Missed Days from Work or School



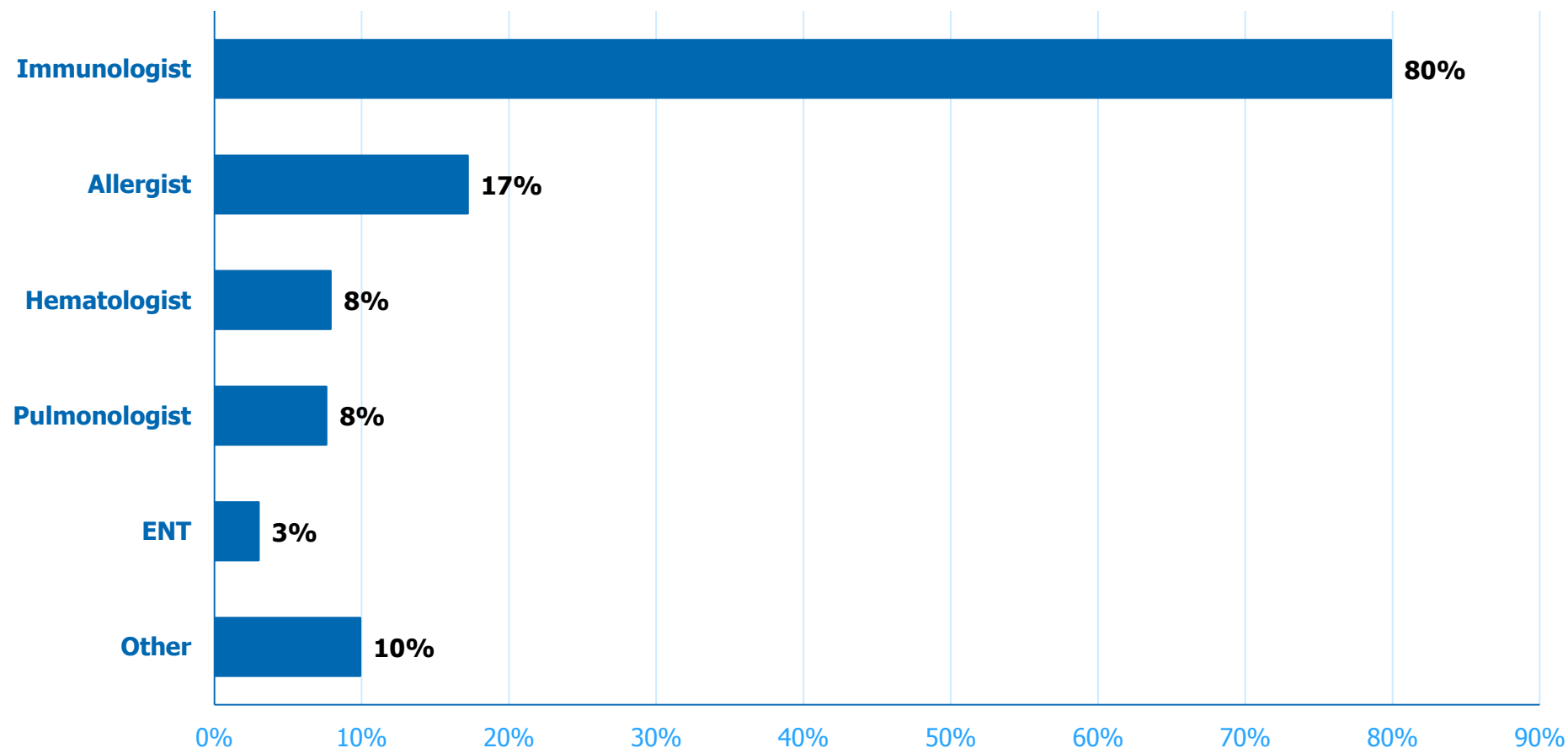
Q17. Not counting hospitalizations, how many days was he/she too sick to work, go to school or perform usual activities in the 12 months prior to diagnosis?

Q60. Not counting hospitalizations, how many days was he/she too sick to work, go to school or perform usual activities in the past 12 months?

Base: Patients who currently use IVIG or SCIG



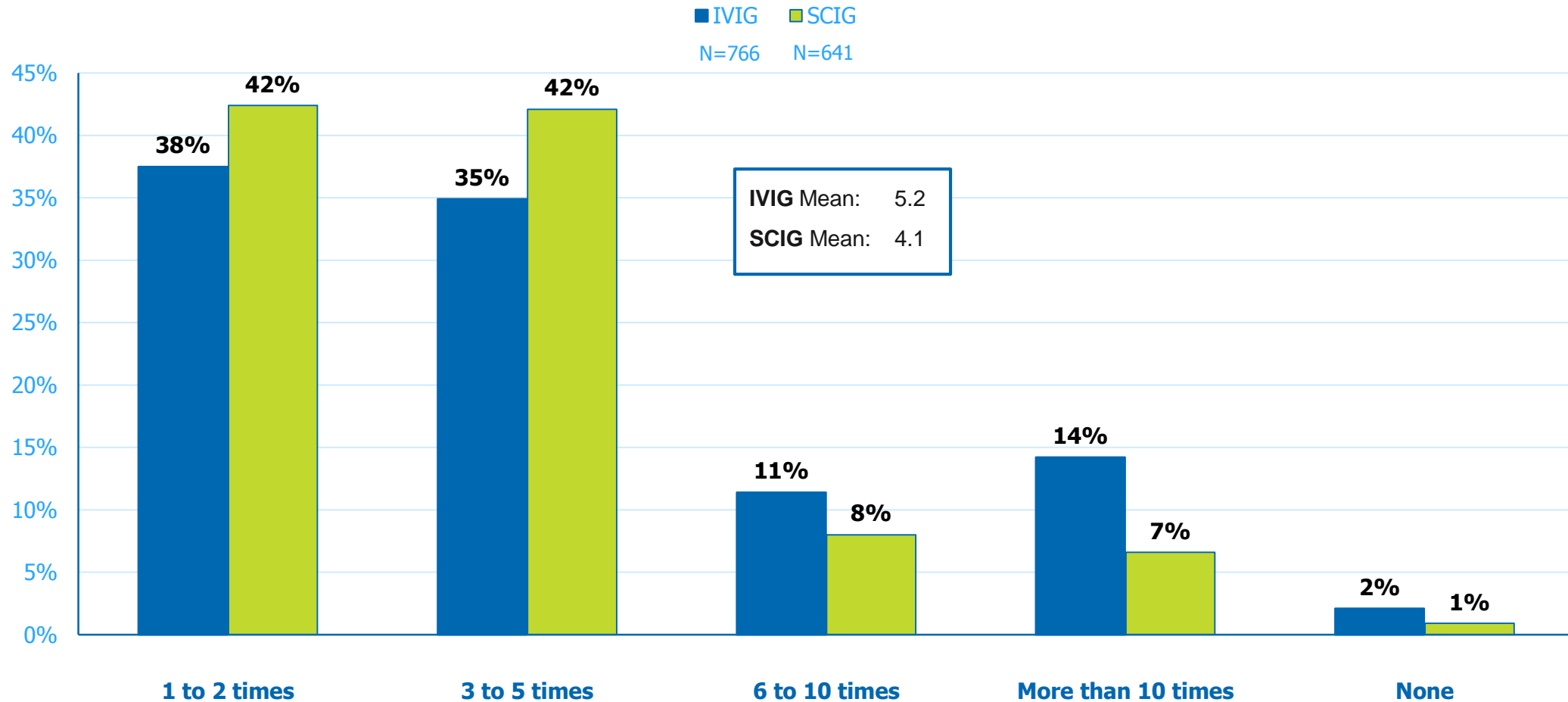
Patient's PI Physician



Q18a. Which type of physician is responsible for the treatment and management of the patient's PI? N=1,413
Base: Patients who currently use IVIG or SCIG

In the Past 12 Months: Number of Times Physician Was Seen *

IVIG vs. SCIG

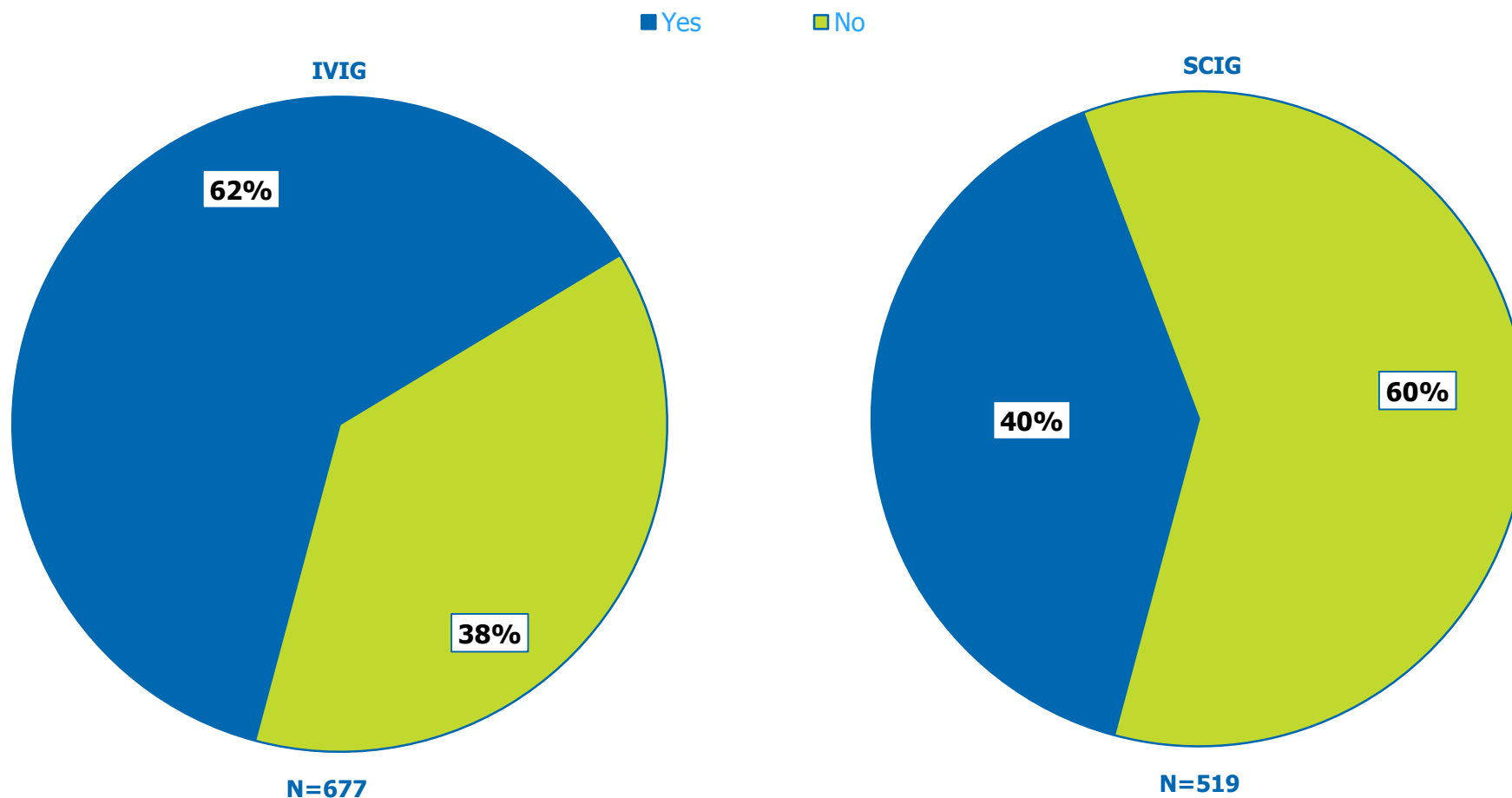


* p<.001

Q18b. How many times over the past 12 months has the patient seen this physician?
Base: Patients who currently use IVIG or SCIG



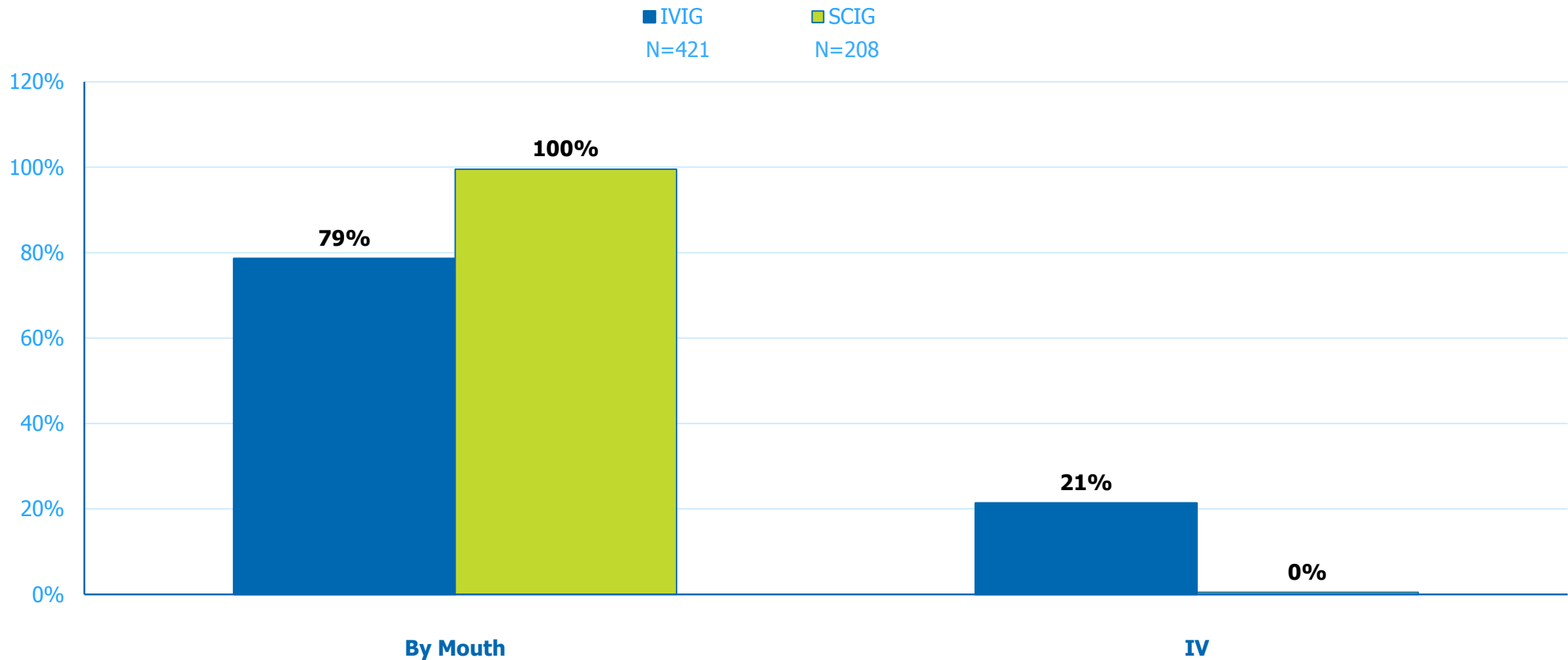
Antihistamine Usually Prescribed Before Ig Therapy Administered



Q37a. Is he/she given medication before Ig therapy, like an antihistamine, cortico-steroid or anti-inflammatory like Tylenol or Motrin, to make it go easier or faster?
Base: Patients who currently use IVIG or SCIG

Antihistamine Usually Prescribed Before Ig Therapy Administered *

IVIG vs. SCIG



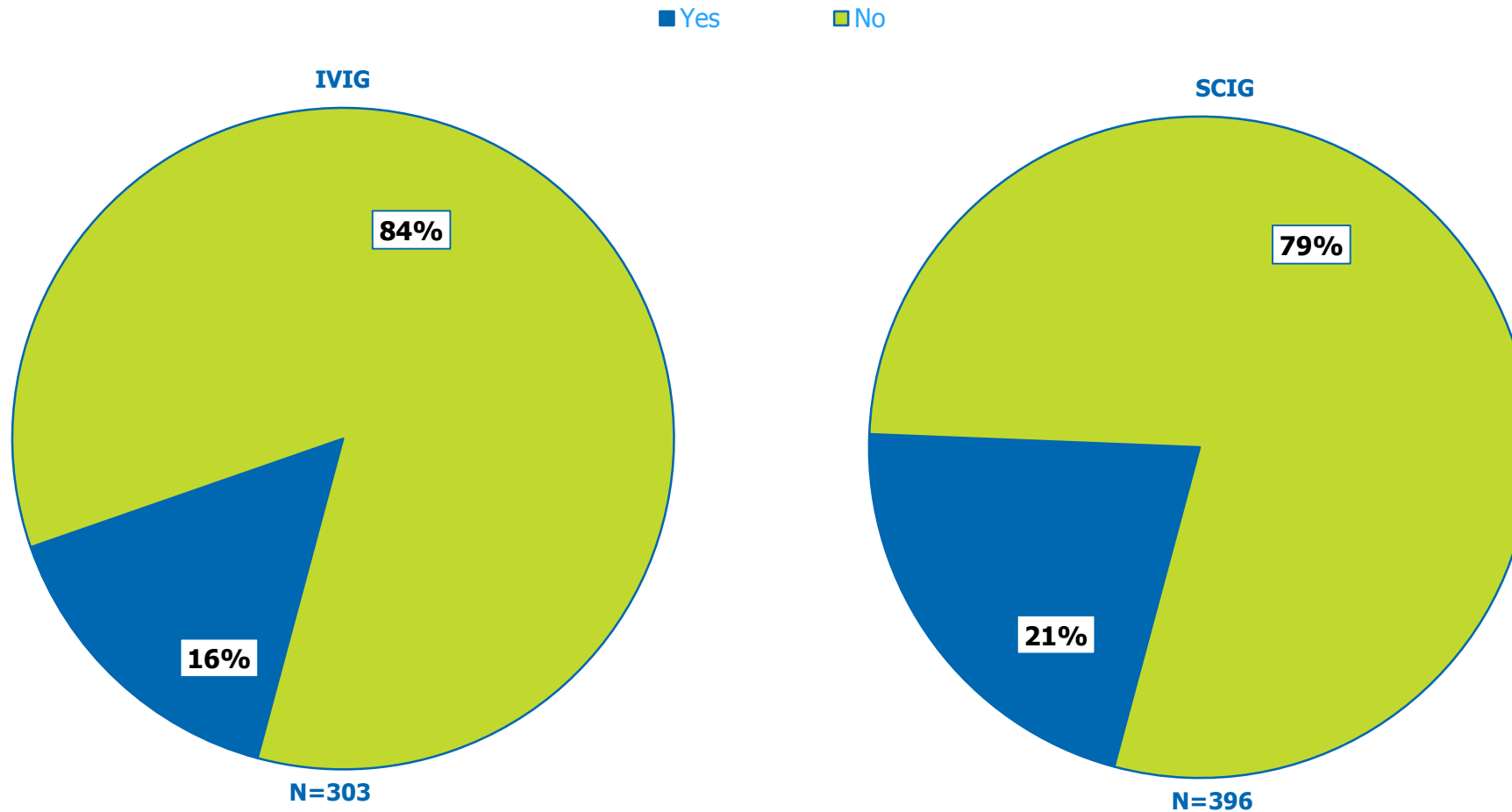
* p<.001

Q37a. Is he/she given medication before Ig therapy, like an antihistamine, cortico-steroid or anti-inflammatory like Tylenol or Motrin, to make it go easier or faster? SELECT ALL THAT APPLY

Base: Patients who currently use IVIG or SCIG that are usually prescribed antihistamines



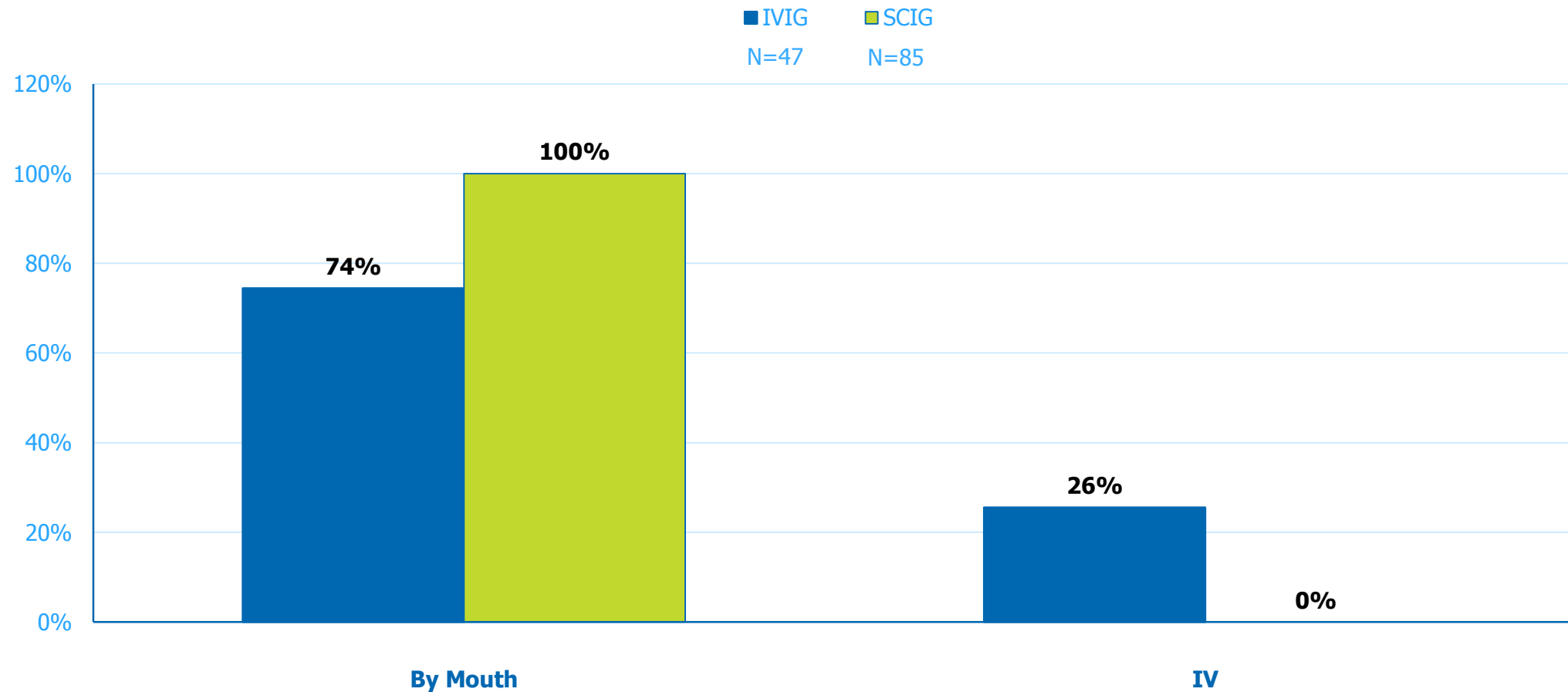
Antihistamine Sometimes Prescribed Before Ig Therapy Administered



Q37a. Is he/she given medication before Ig therapy, like an antihistamine, cortico-steroid or anti-inflammatory like Tylenol or Motrin, to make it go easier or faster?
Base: Patients who currently use IVIG or SCIG

Antihistamine Sometimes Prescribed Before Ig Therapy Administered *

IVIG vs. SCIG



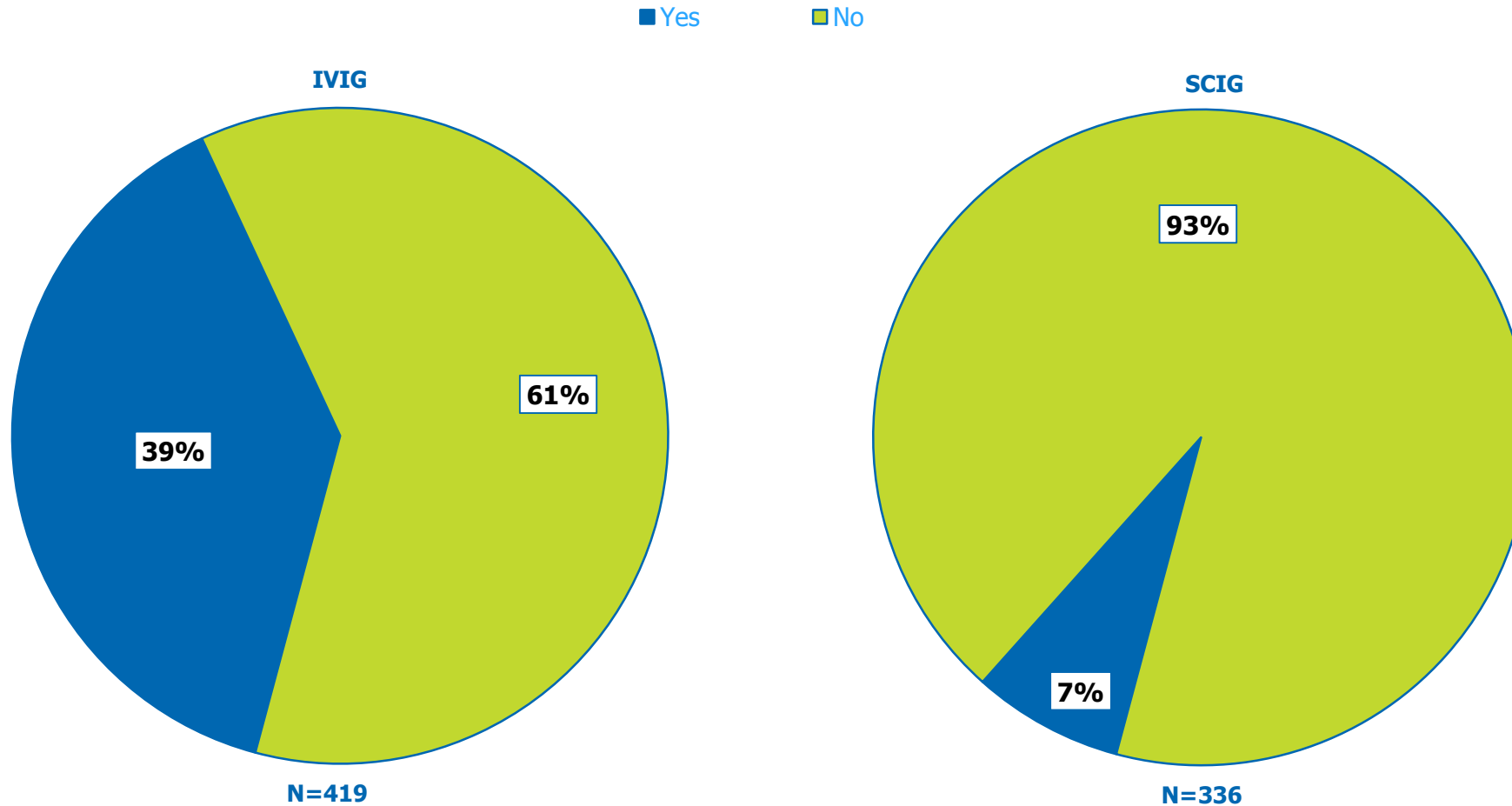
* p<.001

Q37a. Is he/she given medication before Ig therapy, like an antihistamine, cortico-steroid or anti-inflammatory like Tylenol or Motrin, to make it go easier or faster? SELECT ALL THAT APPLY

Base: Patients who currently use IVIG or SCIG that are sometimes prescribed antihistamines



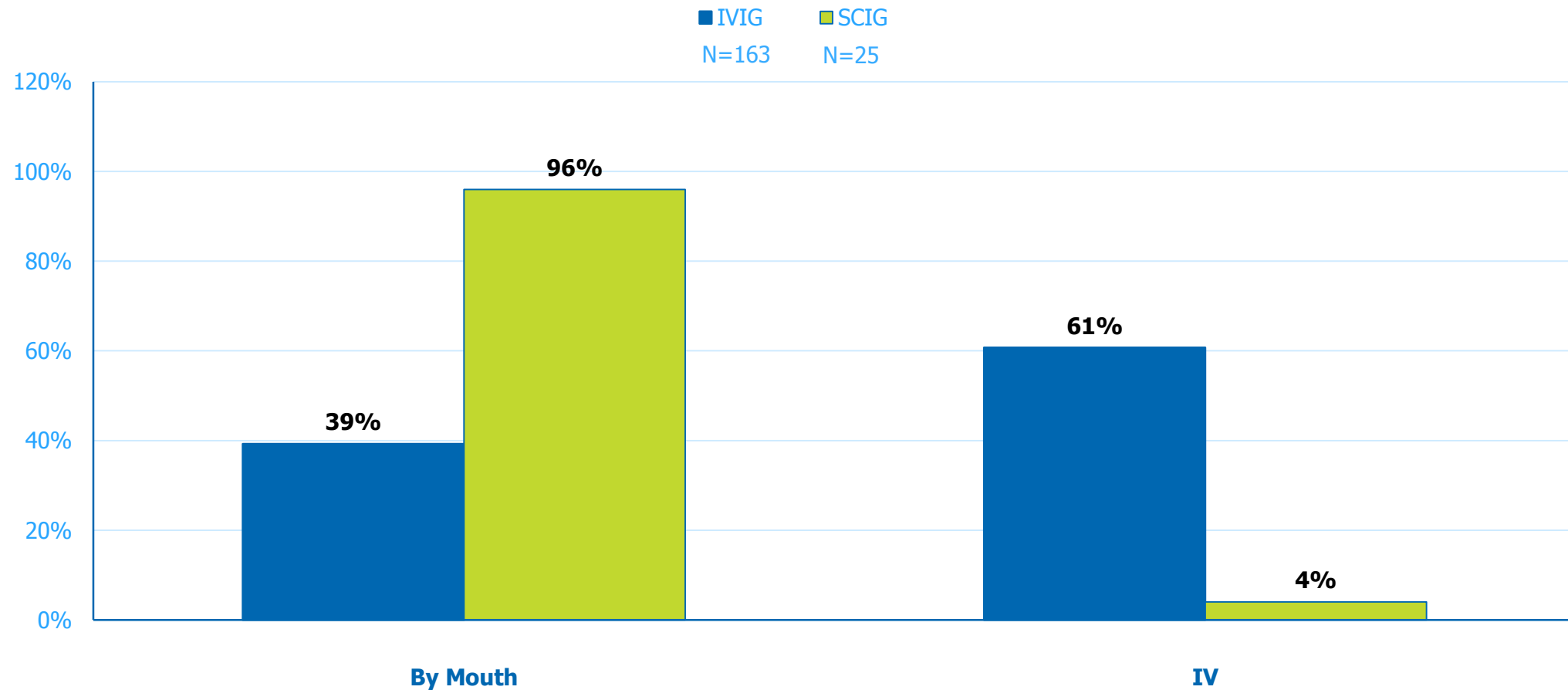
Steroid Usually Prescribed Before Ig Therapy Administered



Q37a. Is he/she given medication before Ig therapy, like an antihistamine, cortico-steroid or anti-inflammatory like Tylenol or Motrin, to make it go easier or faster?
Base: Patients who currently use IVIG or SCIG

Steroid Usually Prescribed Before Ig Therapy Administered*

IVIG vs. SCIG

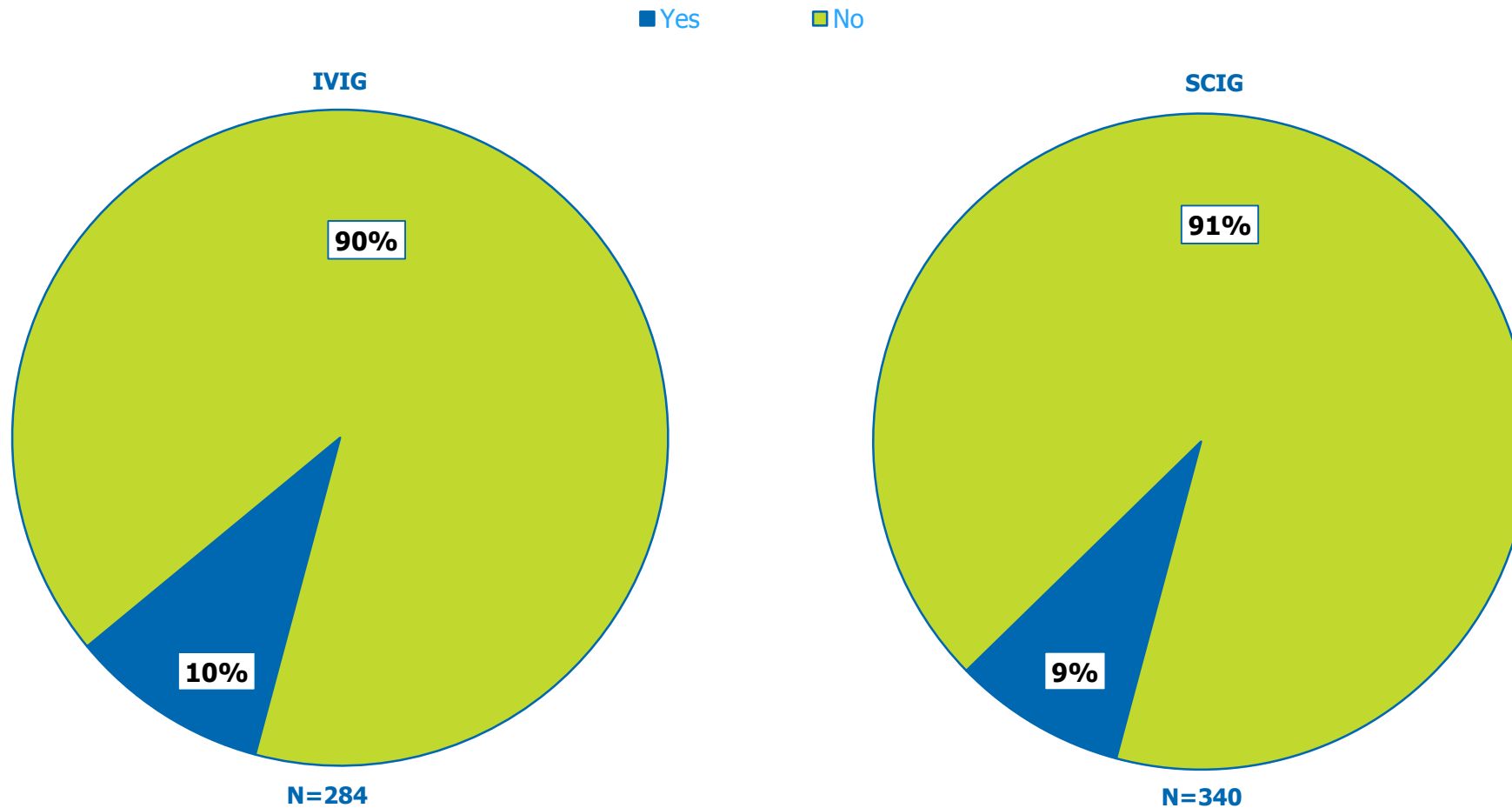


*p<.001

Q37a. Is he/she given medication before Ig therapy, like an antihistamine, cortico-steroid or anti-inflammatory like Tylenol or Motrin, to make it go easier or faster? SELECT ALL THAT APPLY
Base: Patients who currently use IVIG or SCIG that are usually prescribed steroids

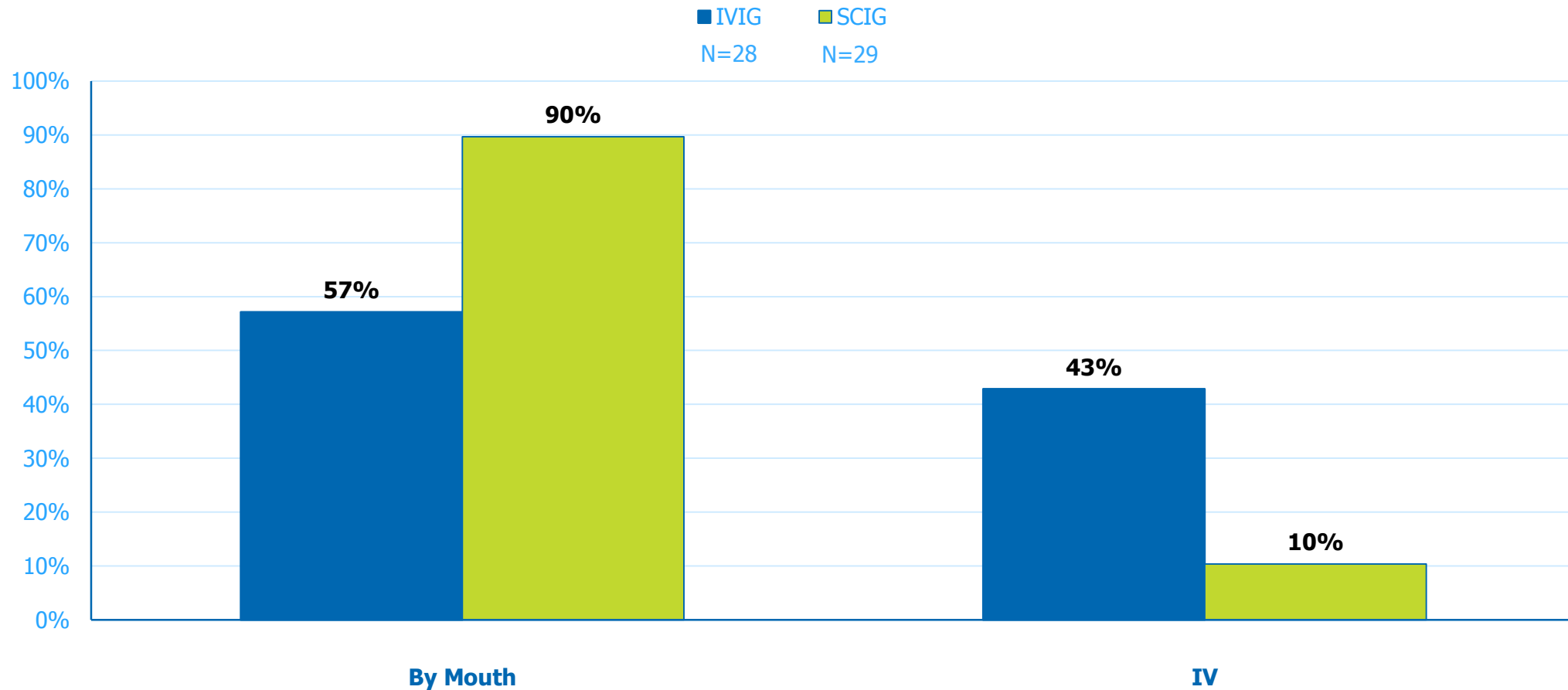


Steroid Sometimes Prescribed Before Ig Therapy Administered



Q37a. Is he/she given medication before Ig therapy, like an antihistamine, cortico-steroid or anti-inflammatory like Tylenol or Motrin, to make it go easier or faster?
Base: Patients who currently use IVIG or SCIG

Steroid Sometimes Prescribed Before Ig Therapy Administered * IVIG vs. SCIG



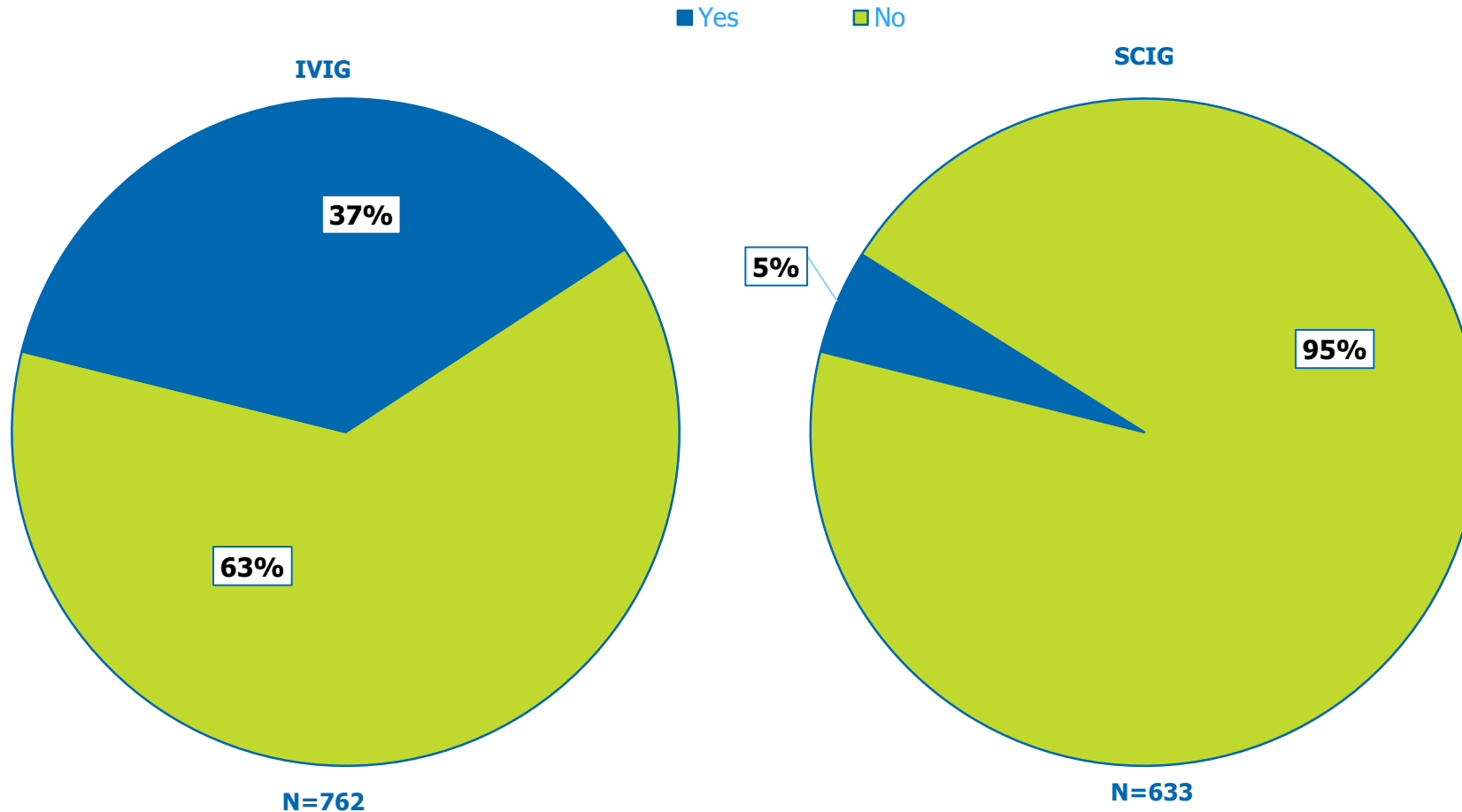
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Q37a. Is he/she given medication before Ig therapy, like an antihistamine, cortico-steroid or anti-inflammatory like Tylenol or Motrin, to make it go easier or faster? SELECT ALL THAT APPLY

Base: Patients who currently use IVIG or SCIG that are sometimes prescribed steroids



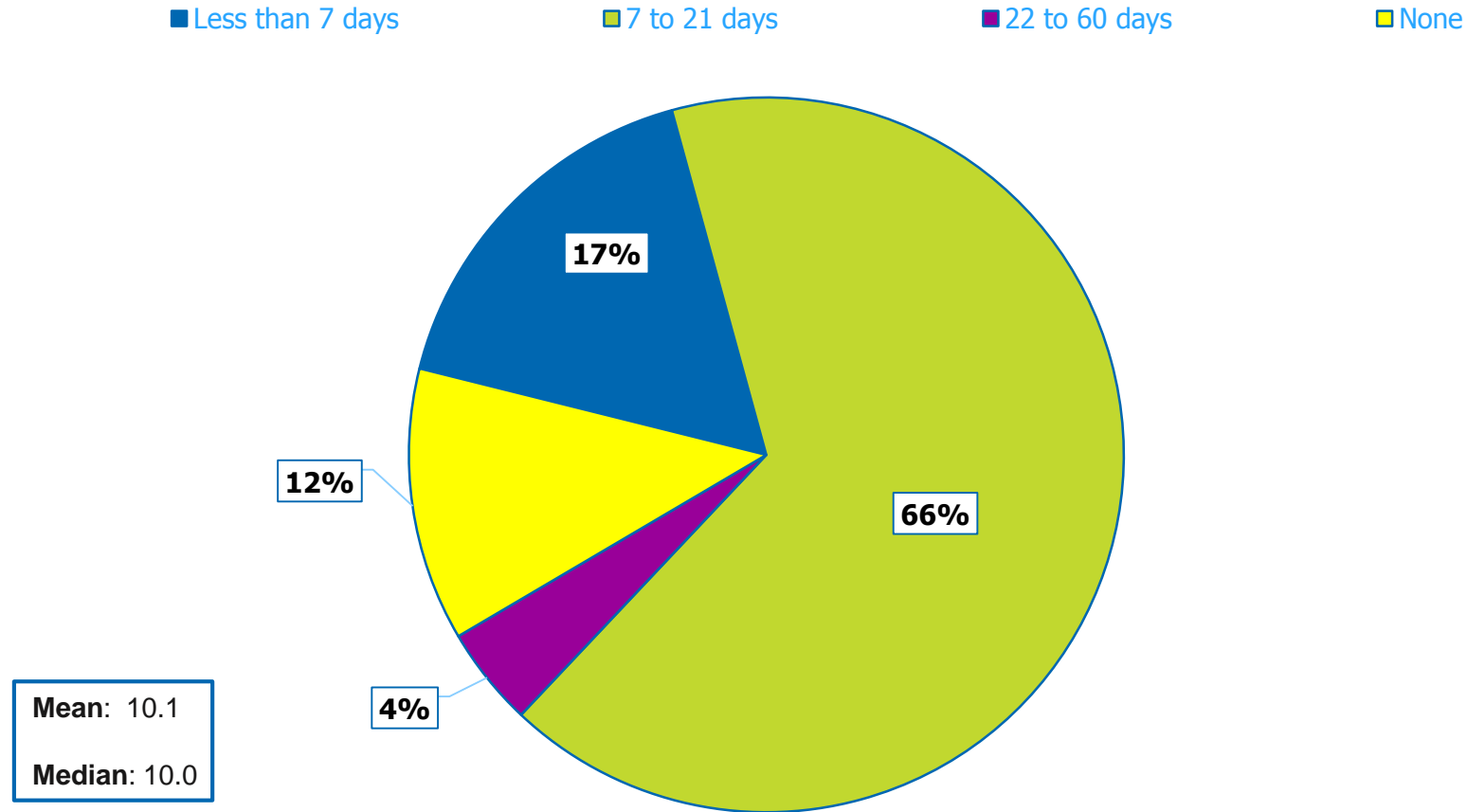
Missed Work or School Due to Ig Therapy*



* p<.001

Q38a. Does the patient (parent/caretaker) need to take off from school or work to get their Ig therapy?
Base: Patients who currently use IVIG or SCIG

Missed Days from School Due to Ig Therapy



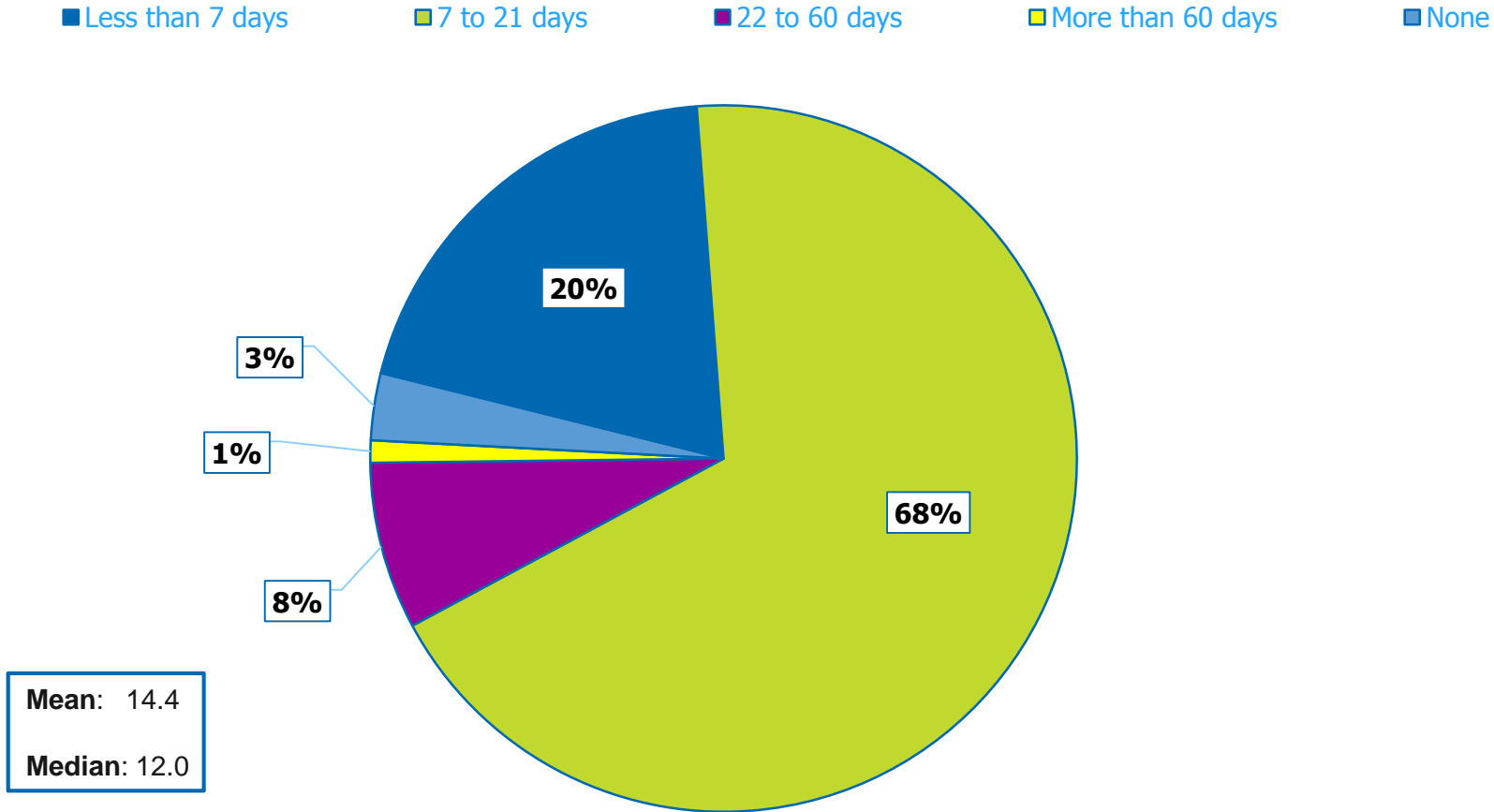
Q38b. How many days in the past 12 months has the patient (parent/caretaker) needed to take off work or miss school to get their Ig therapy? N=89

Base: Patients who currently use IVIG or SCIG who missed days from school

Note: Patients with PI and Parents/Caregivers who are too disabled to work or retired were excluded



Missed Days from Work Due to Ig Therapy



Q38b. How many days in the past 12 months has the patient (parent/caretaker) needed to take off work or miss school to get their Ig therapy? N=196

Base: Patients who currently use IVIG or SCIG who missed days from school

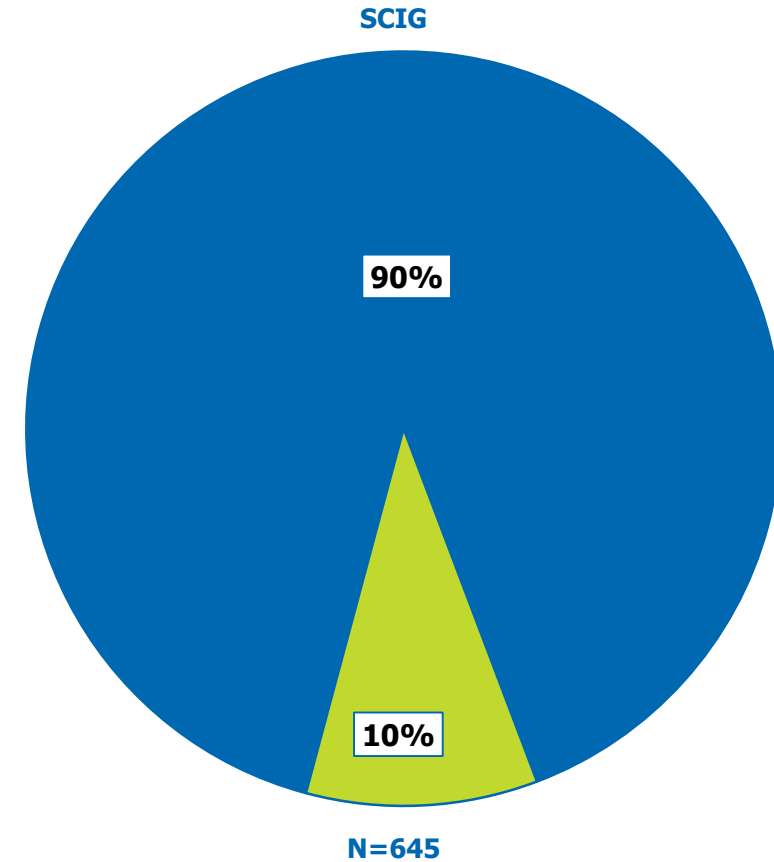
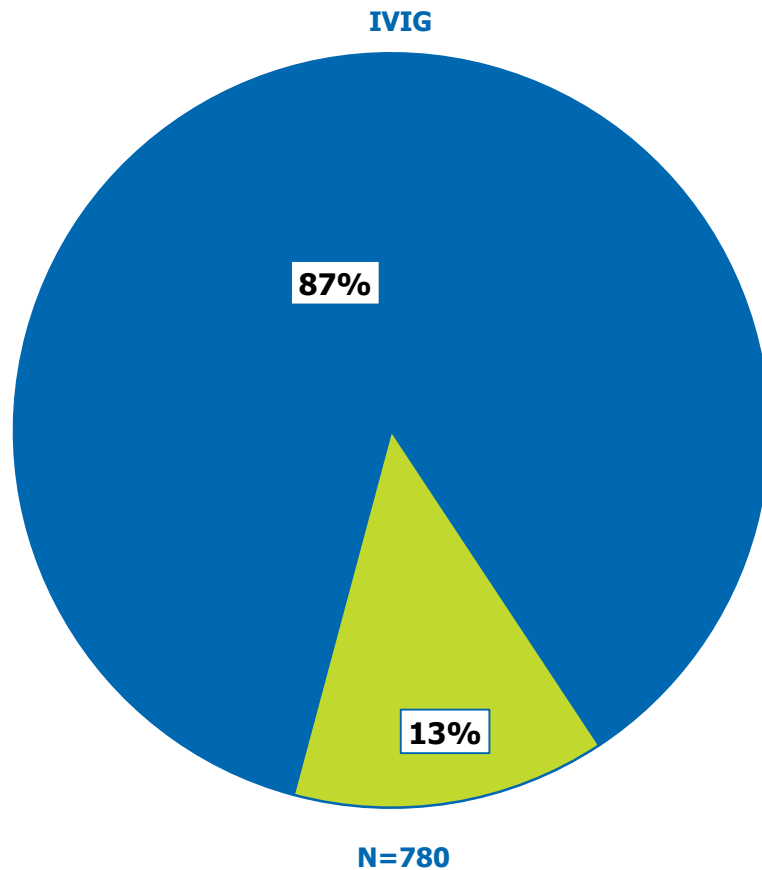
Note: Patients with PI and Parents/Caregivers who are too disabled to work or retired were excluded



Side Effects of Ig Therapy

■ Yes, experienced side effects during, after or both

■ No, did not experience ANY side effects at any time



Q39. During the past 12 months, has he/she experienced any of the following during or after Ig therapy?
Base: Patients who currently use IVIG or SCIG

Side Effects of Ig Therapy

IVIG

N=675

Side Effect	%	Side Effect	%
Fatigue	71%	Increase in blood pressure	17%
Headache	69%	Muscle spasms	13%
Muscle aches	39%	Abdominal pain	13%
Chills	35%	Drop in blood pressure	13%
Weakness	29%	Swelling at infusion site	12%
Nausea	28%	Wheezing	9%
Migraine headache	28%	Hives	8%
Fever	25%	Vomiting	8%
Dizziness	21%	Blood in tubing	3%
Anxiety	19%	Kidney problems	2%
Diarrhea	19%	Hepatitis	0.4%

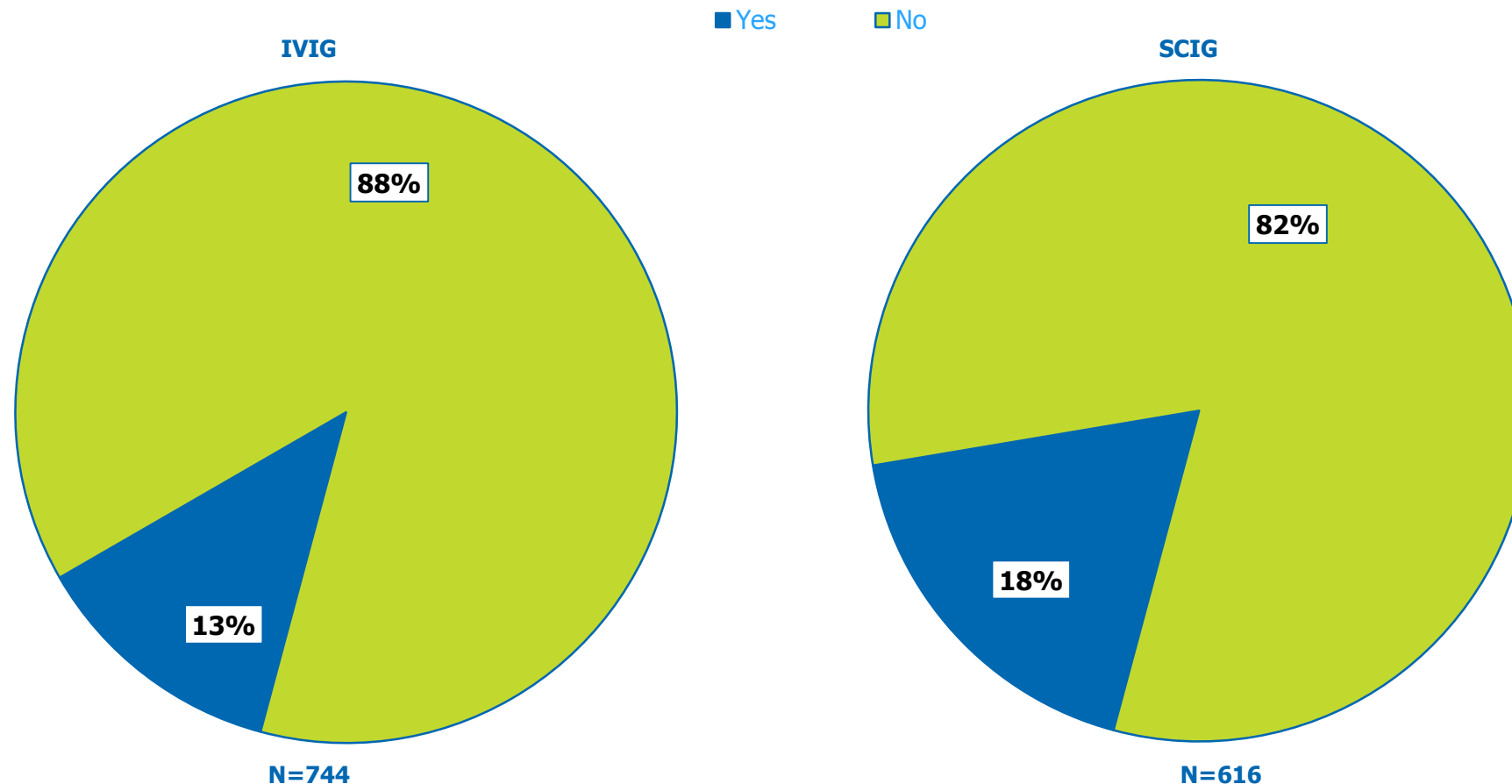
SCIG

N=581

Side Effect	%	Side Effect	%
Redness at infusion site	78%	Nausea	16%
Swelling at infusion site	75%	Fever	15%
Fatigue	54%	Dizziness	15%
Headache	47%	Muscle spasms	10%
Blood in tubing	32%	Hives	8%
Muscle aches	29%	Increase in blood pressure	8%
Chills	24%	Drop in blood pressure	5%
Abdominal pain	24%	Wheezing	4%
Migraine headache	21%	Kidney problems	3%
Anxiety	19%	Vomiting	3%
Weakness	17%	Hepatitis	1%

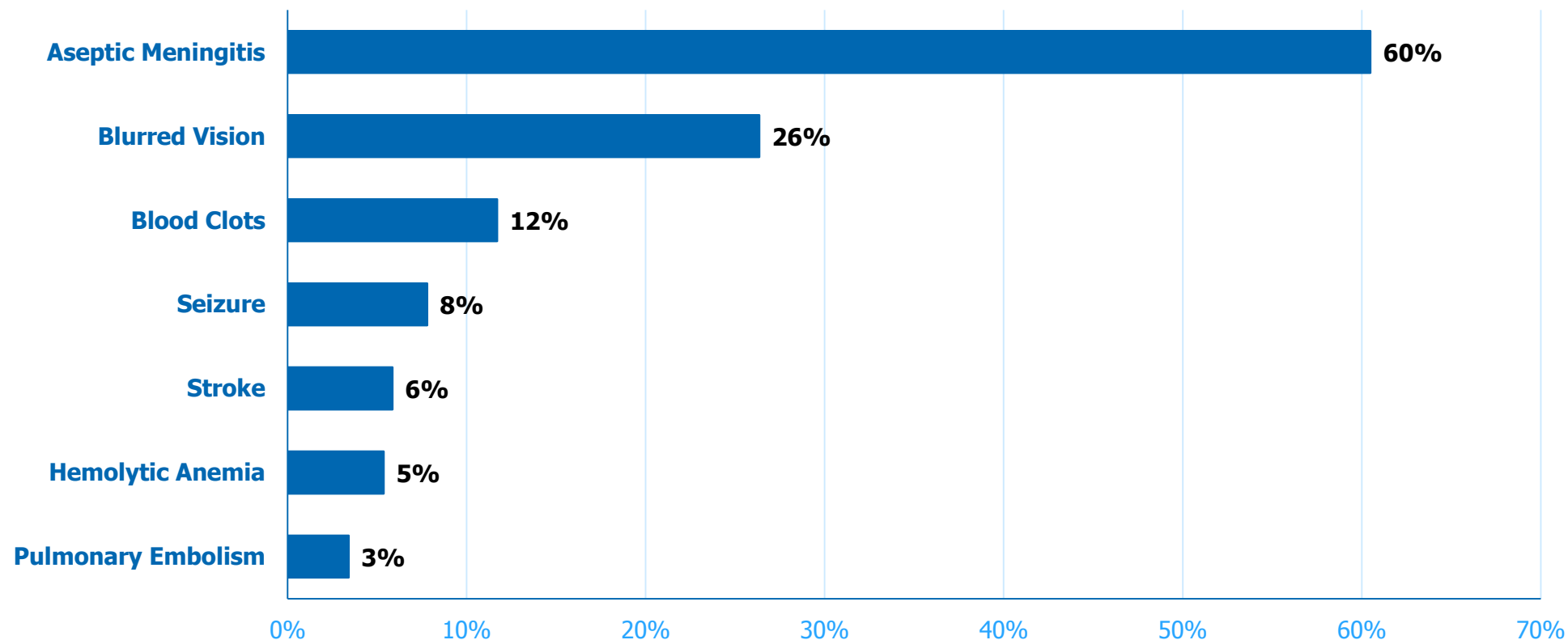
Q39. During the past 12 months, has he/she experienced any of the following during or after Ig therapy?
Base: Patients who currently use IVIG or SCIG who experienced a side effect

Serious Side Effects or Reactions



Q40a. Has the patient ever had any of the following serious side-effects or reactions from their Ig?
Base: Patients who currently use IVIG or SCIG that experienced a serious side effect or reaction

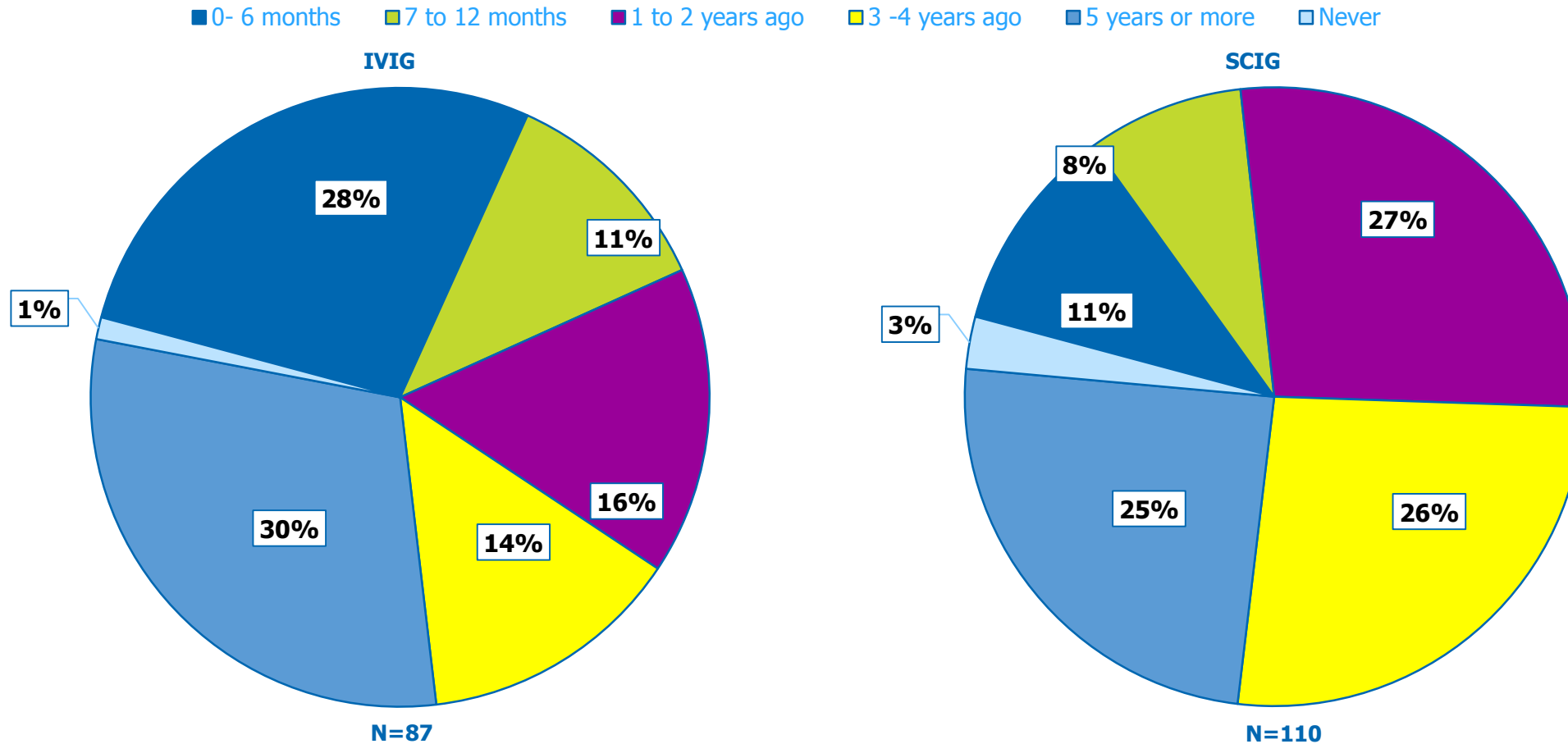
Serious Side Effects or Reactions



Q40a. Has the patient ever had any of the following serious side-effects or reactions from their Ig?
PLEASE SELECT ALL THAT APPLY N=205
Base: Patients who currently use IVIG or SCIG that experienced a serious side effect or reaction

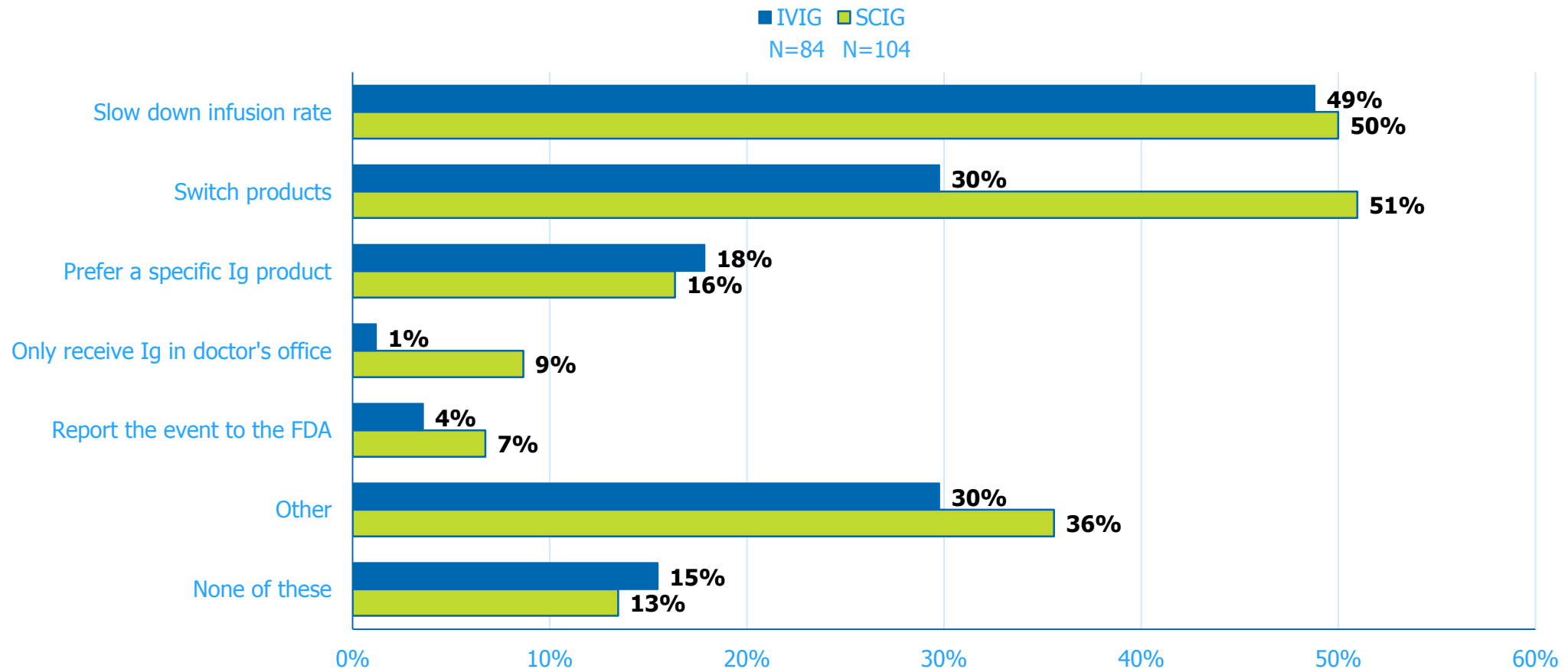


Last Time Serious Side Effects or Reactions Occurred



Q40b. When was the most recent time that he/she had a serious side effect or reaction from their Ig?
Base: Patients who currently use IVIG or SCIG who experienced a serious side effect or reaction

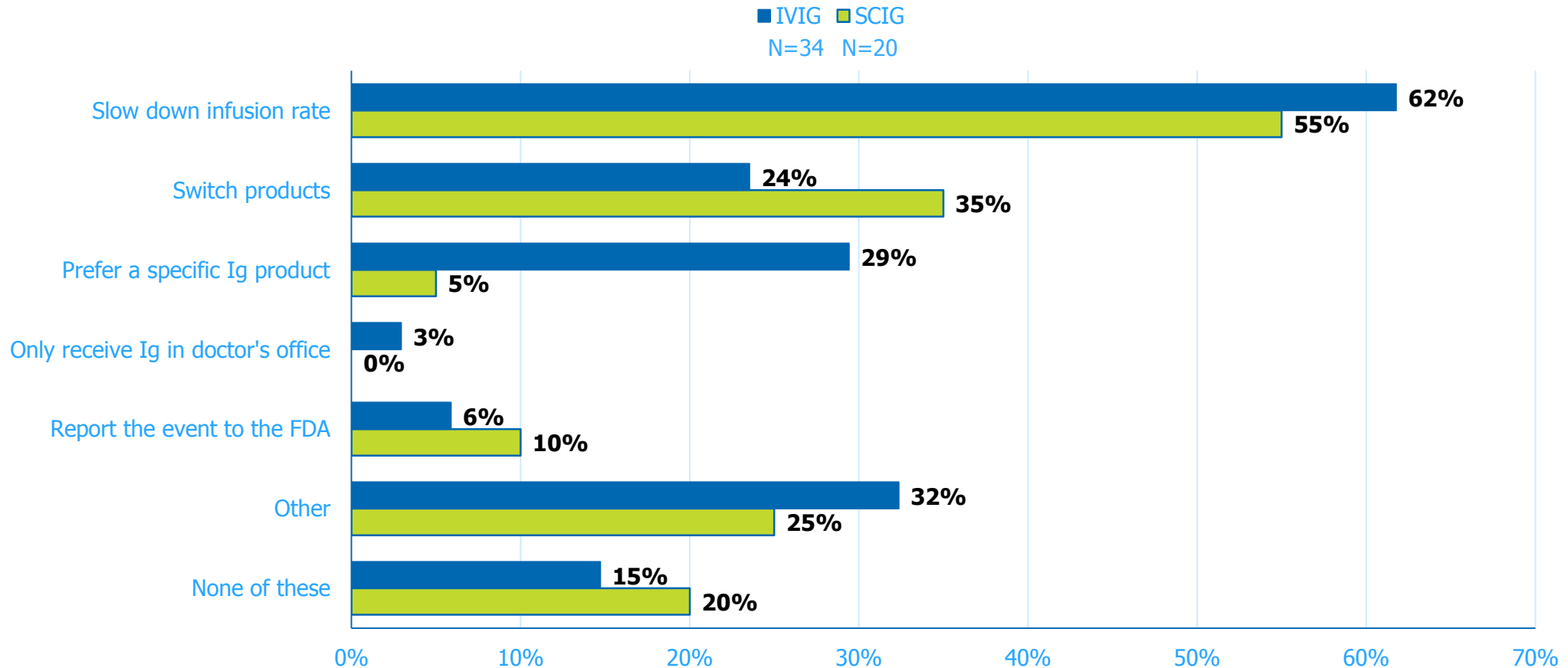
Serious Side Effects or Reactions Caused the Patient to...



Q40c. Did the patient's side effect or reaction cause him/her to ... SELECT ALL THAT APPLY
Base: Patients who currently use IVIG or SCIG IM who experienced a serious side effect or reaction



In the Past 12 Months Serious Side Effects or Reactions Caused the Patient to...

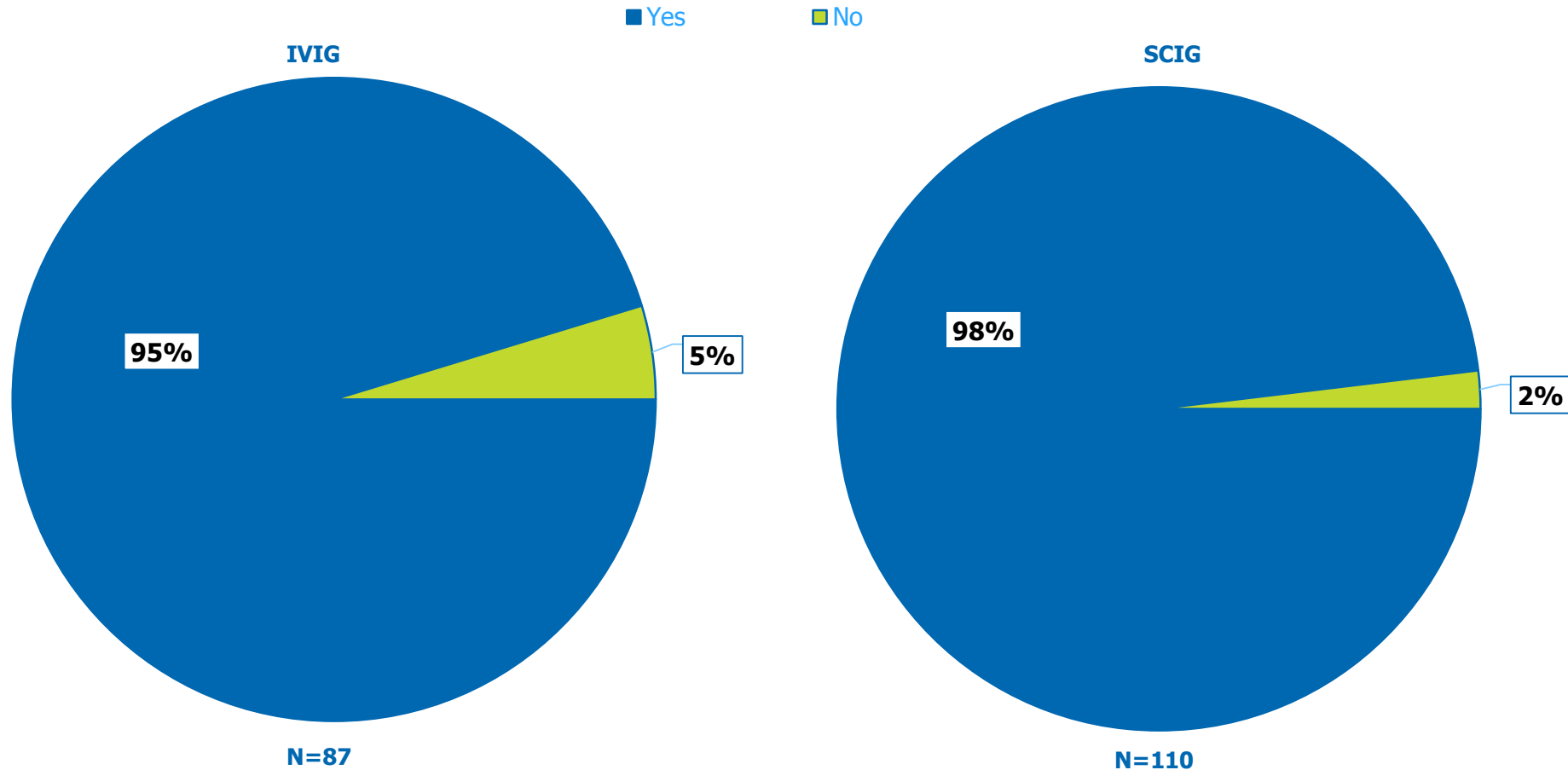


Q40c. Did the patient's side effect or reaction cause him/her to ... SELECT ALL THAT APPLY

Base: Patients who currently use IVIG or SCIG IM who experienced a serious side effect or reaction in the past 12 months



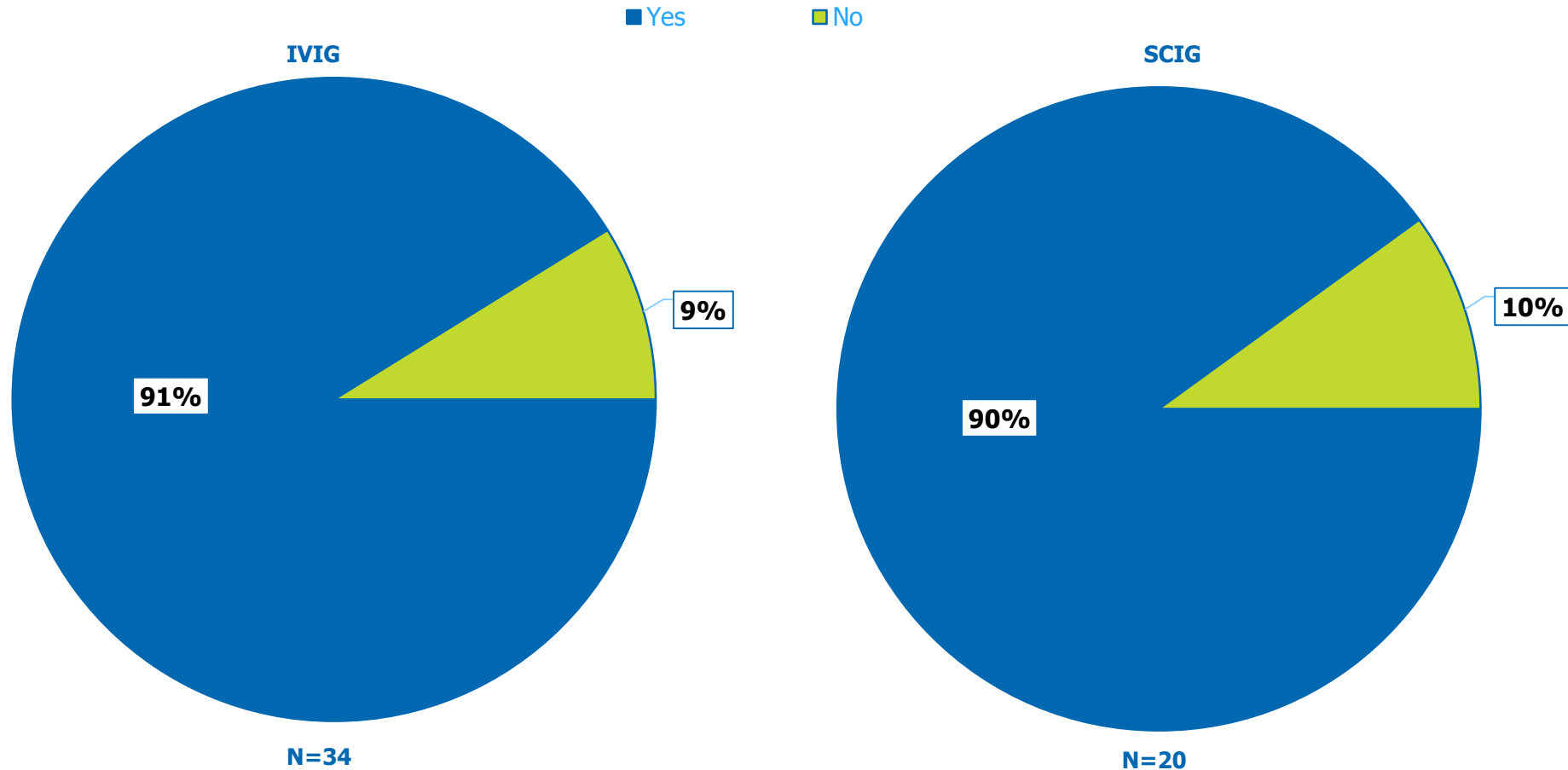
Was Doctor Told the Patient had a Serious Side-Effect or Reaction?



Q40d. Was the doctor told about the patient's serious side-effect or reaction?

Base: Patients who currently use IVIG or SCIG who experienced a serious side effect or reaction

In the Past 12 Months Was Doctor Told the Patient had a Serious Side-Effect or Reaction?

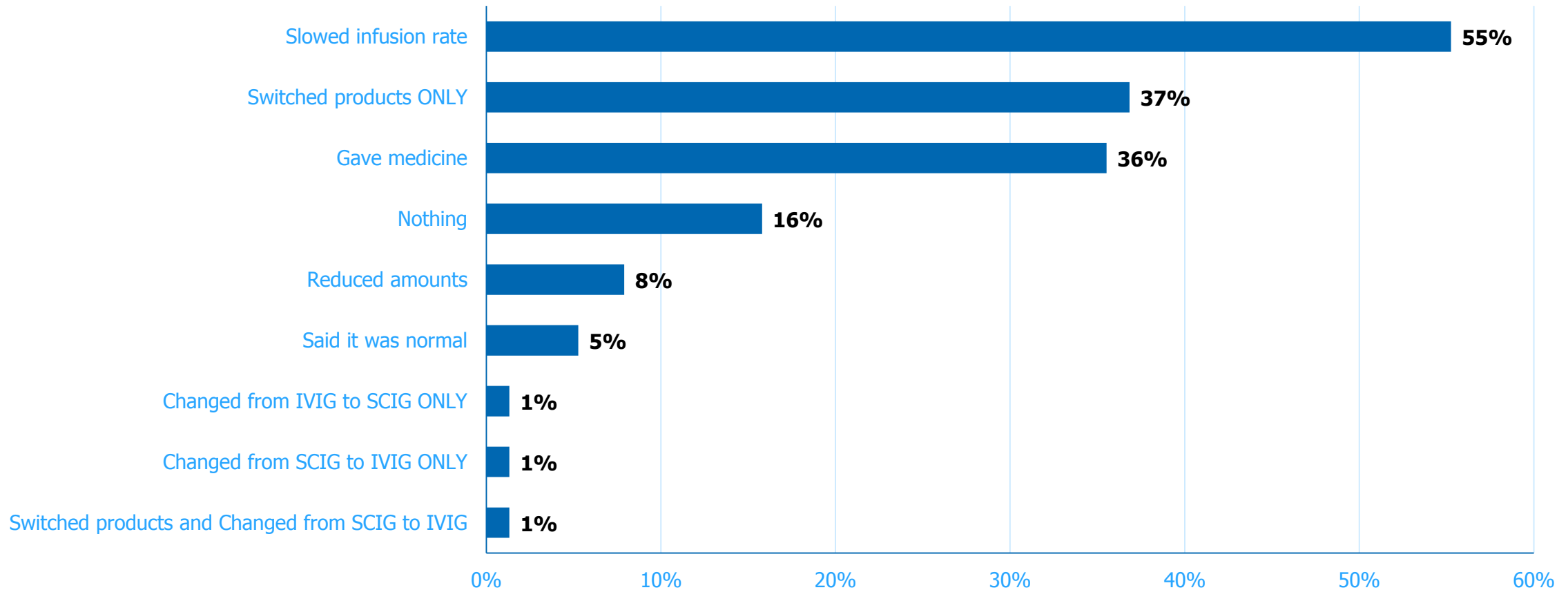


Q40d. Was the doctor told about the patient's serious side-effect or reaction?

Base: Patients who currently use IVIG or SCIG who experienced a serious side effect or reaction in the past 12 months

IVIG

What Did the Doctor Do?

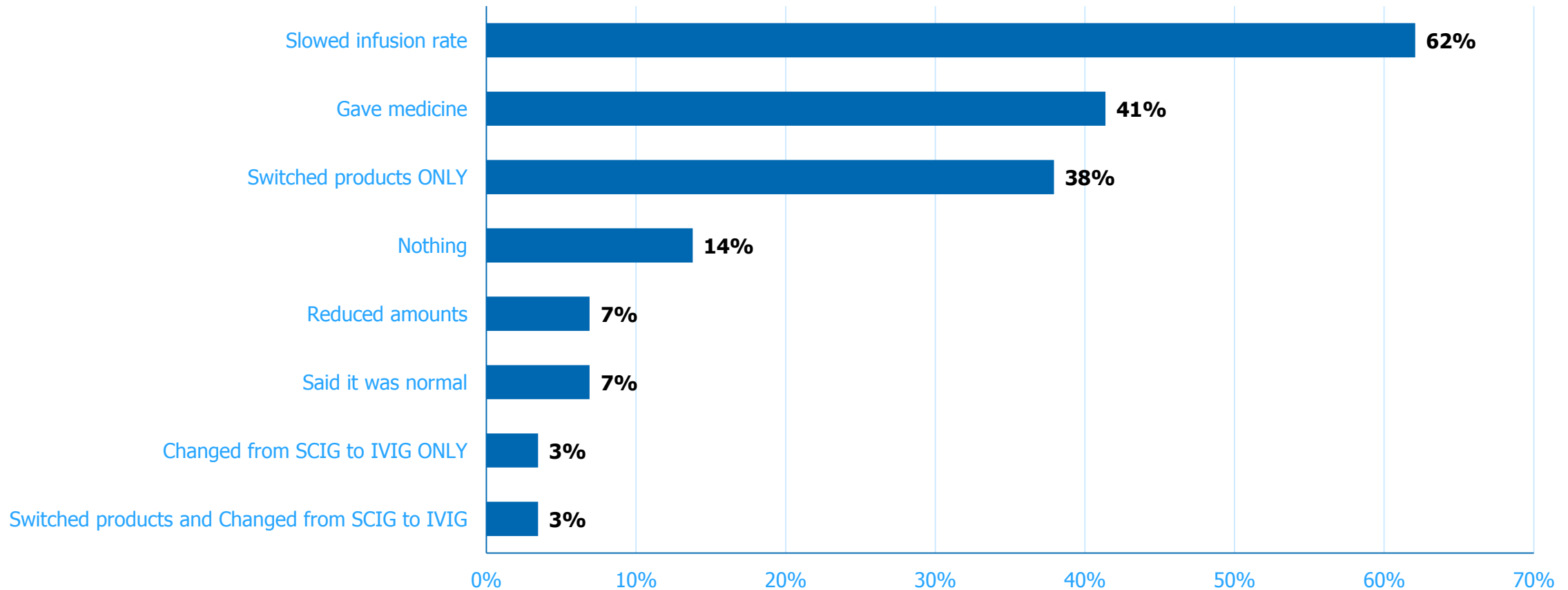


Q40e. What did the doctor do? N=76

Base: Patients who currently use IVIG who experienced a serious side effect or reaction



IVIG - In the Past 12 Months What Did the Doctor Do?



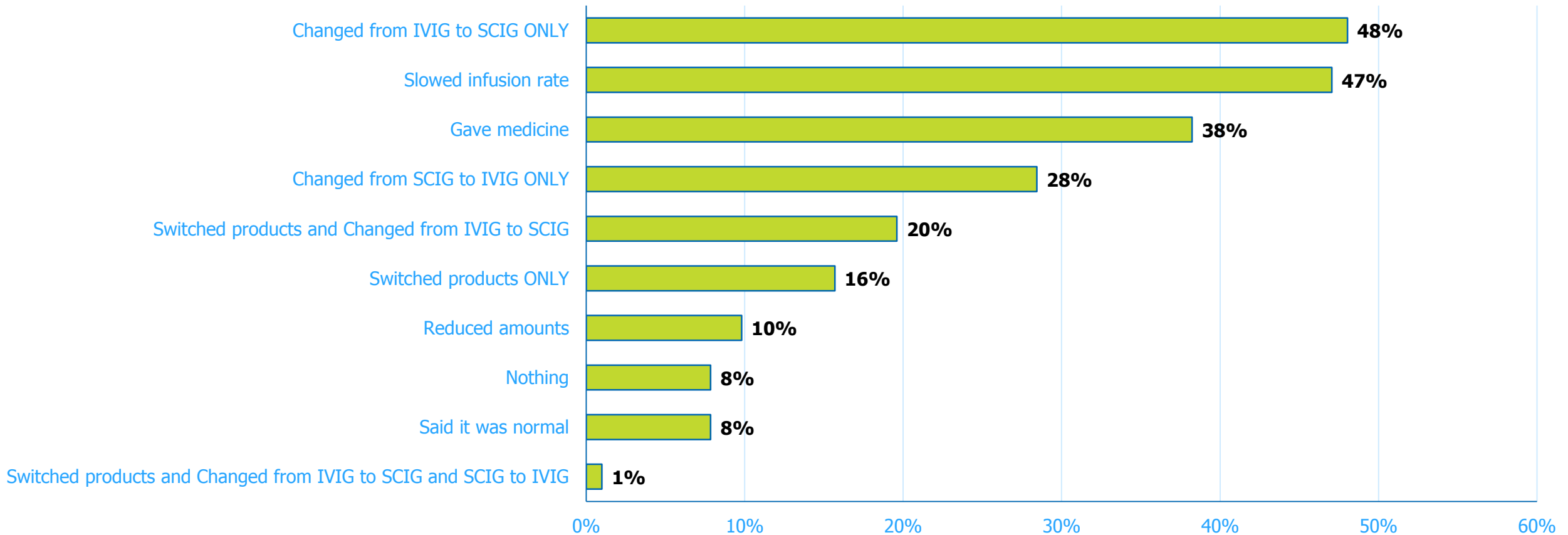
Q40e. What did the doctor do? N=29

Base: Patients who currently use IVIG who experienced a serious side effect or reaction in the past 12 months



SCIG

What Did the Doctor Do?

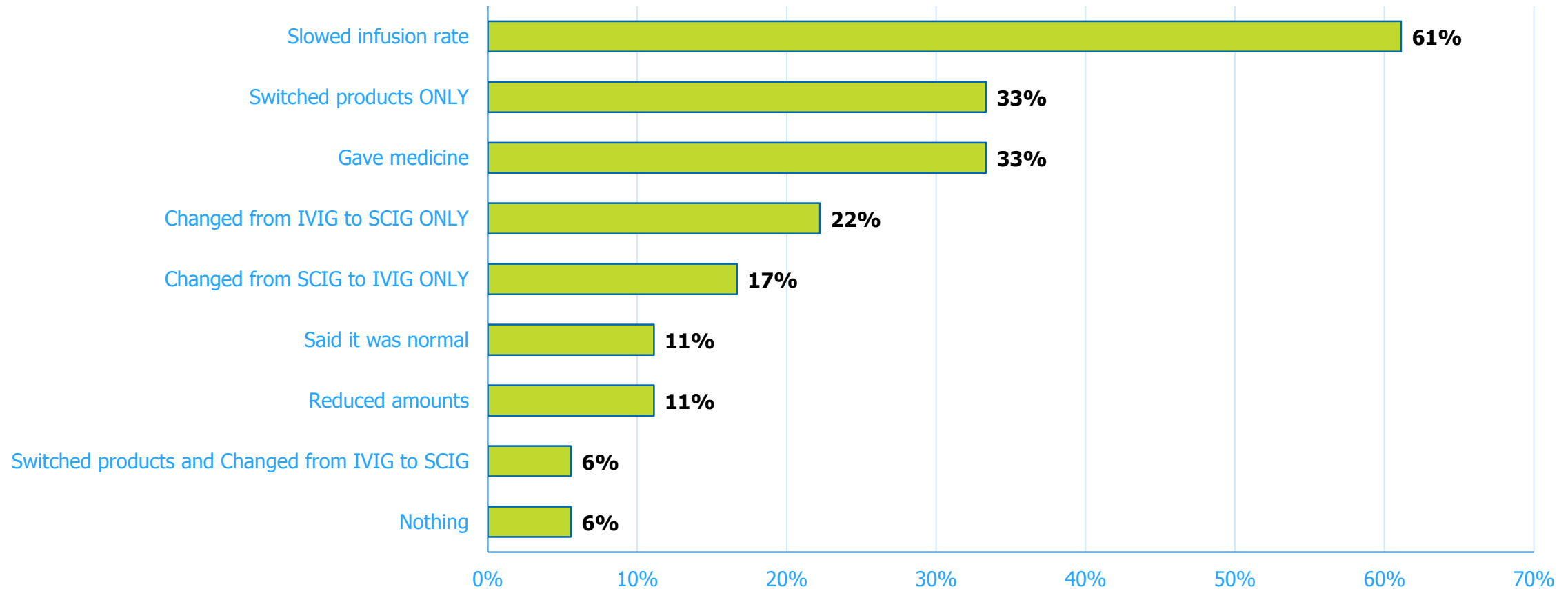


Q40e. What did the doctor do? N=102

Base: Patients who currently use SCIG who experienced a serious side effect or reaction



SCIG - In the Past 12 Months What Did the Doctor Do?



Q40e. What did the doctor do? N=18

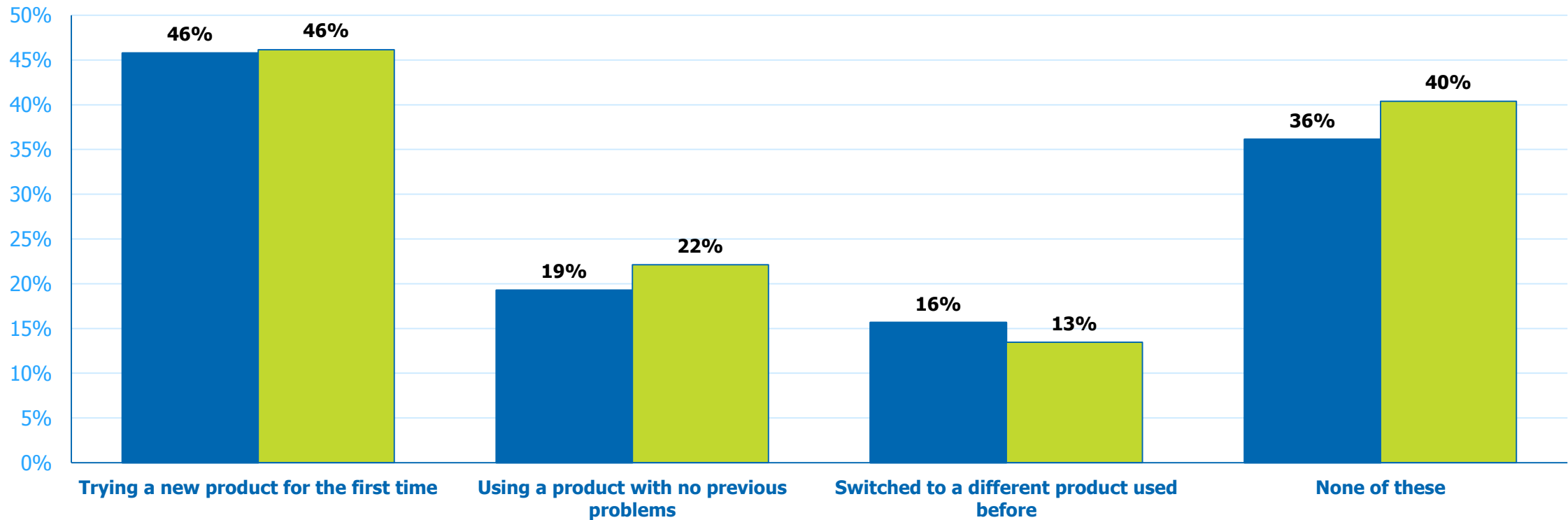
Base: Patients who currently use SCIG who experienced a serious side effect or reaction



Patient had a Serious Side-Effect or Reaction When...

■ IVIG
N=83

■ SCIG
N=104



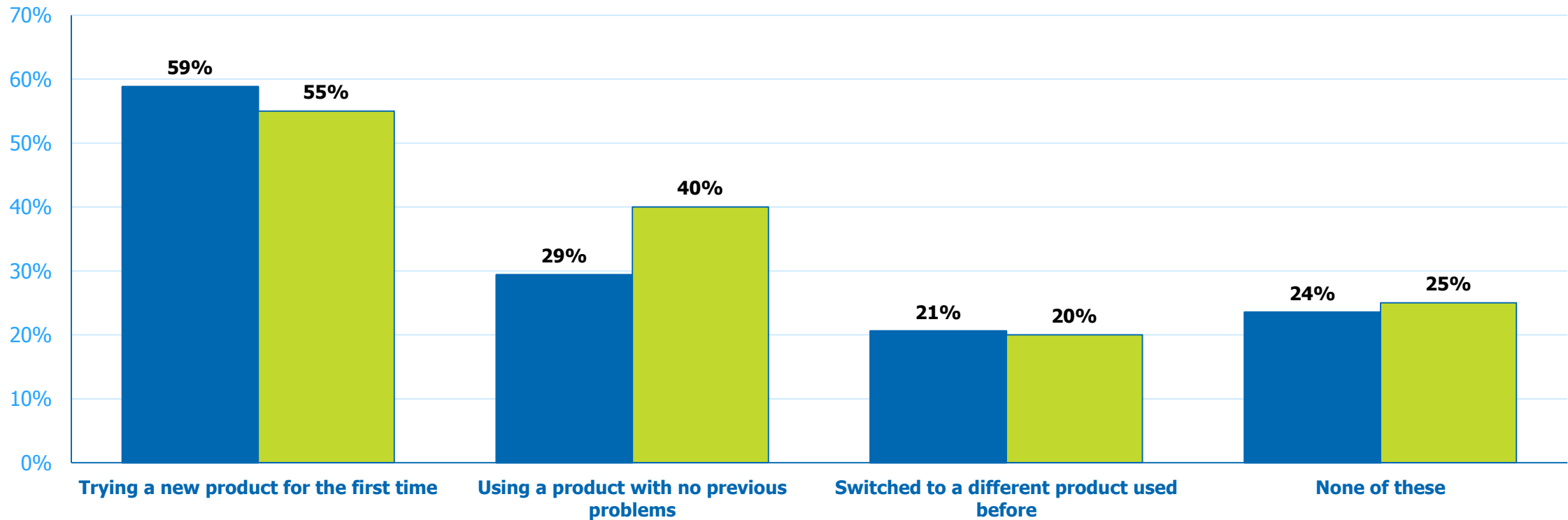
Q40f. Has the patient ever had a serious side effect or reaction from Ig therapy when... SELECT ALL THAT APPLY
Base: Patients who currently use IVIG or SCIG who experienced a serious side effect or reaction



In the Past 12 Months Patient had a Serious Side-Effect or Reaction When...

■ IVIG
N=34

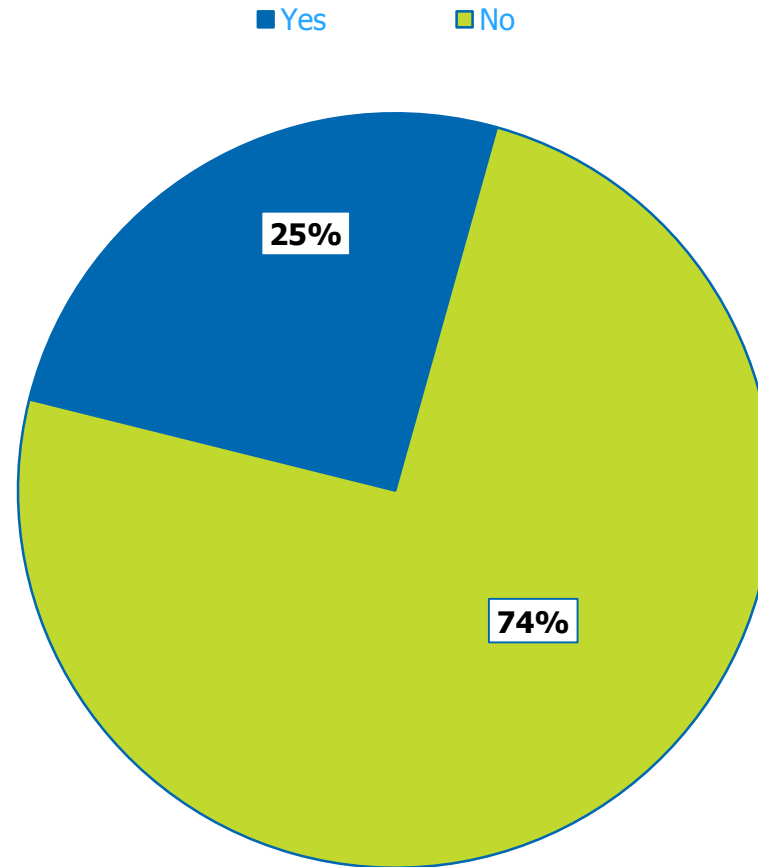
■ SCIG
N=20



Q40f. Has the patient ever had a serious side effect or reaction from Ig therapy when... SELECT ALL THAT APPLY
Base: Patients who currently use IVIG or SCIG who experienced a serious side effect or reaction in the past 12 months



Missed Work or School Due to Reaction from Ig Therapy

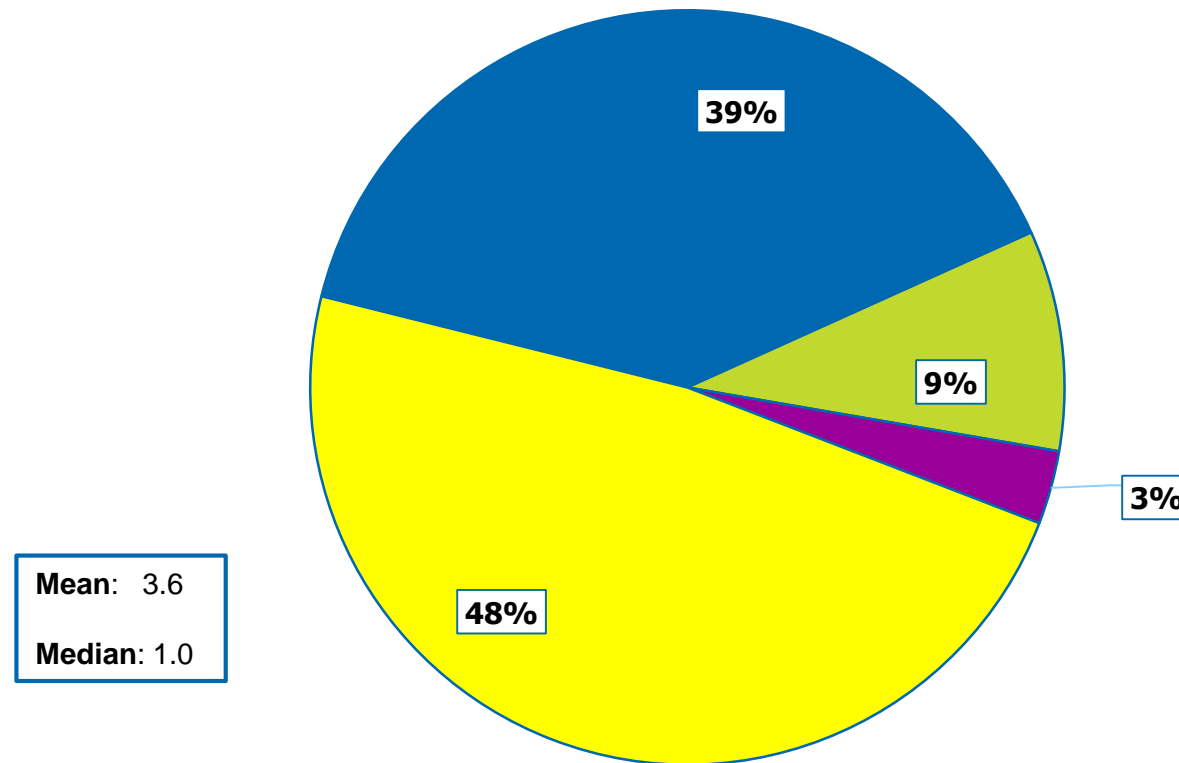


Q41a. Has the patient (parent/caretaker of a patient) ever missed school or work due to a reaction from their Ig therapy? N=1,381
Base: Patients who currently use IVIG or SCIG



Missed Days from School Due to Reaction from Ig Therapy

■ Less than 1 week ■ 7 to 21 days ■ 22 to 60 days ■ None

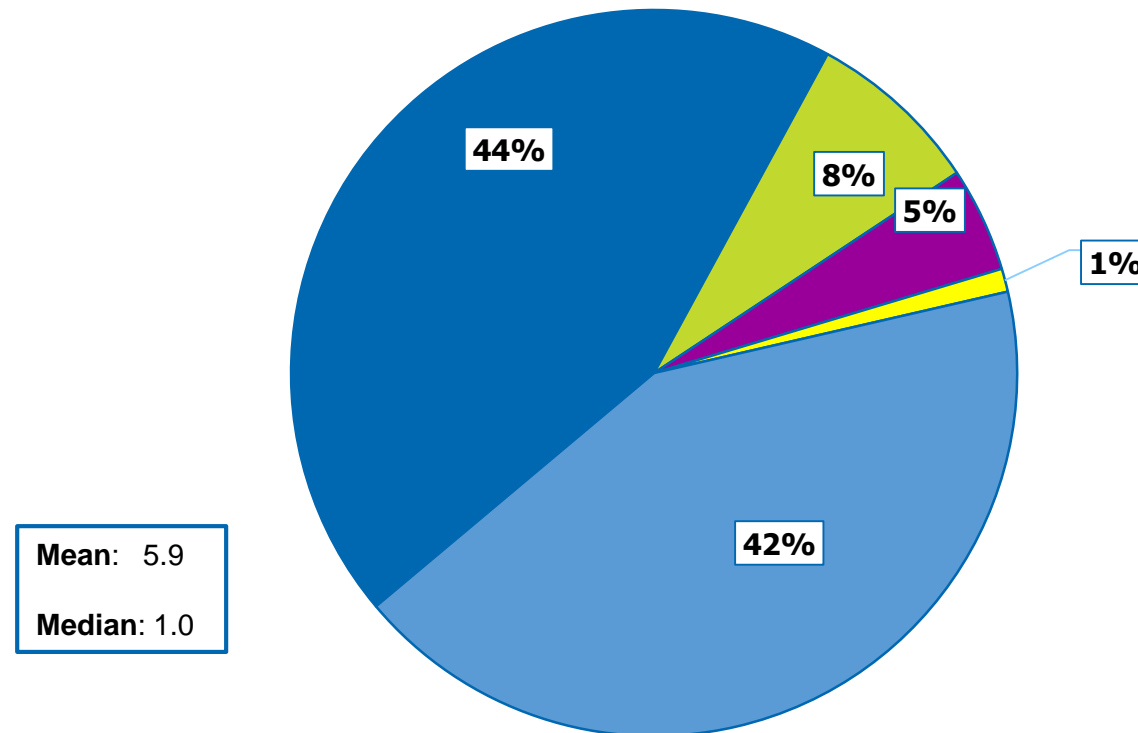


Q41b. How many days in the past 12 months has the patient (parent/caretaker of a patient) missed school or work due to reactions from Ig therapy? N=127
Base: Patients who currently use IVIG or SCIG who missed days from school



Missed Days from Work Due to Reaction from Ig Therapy

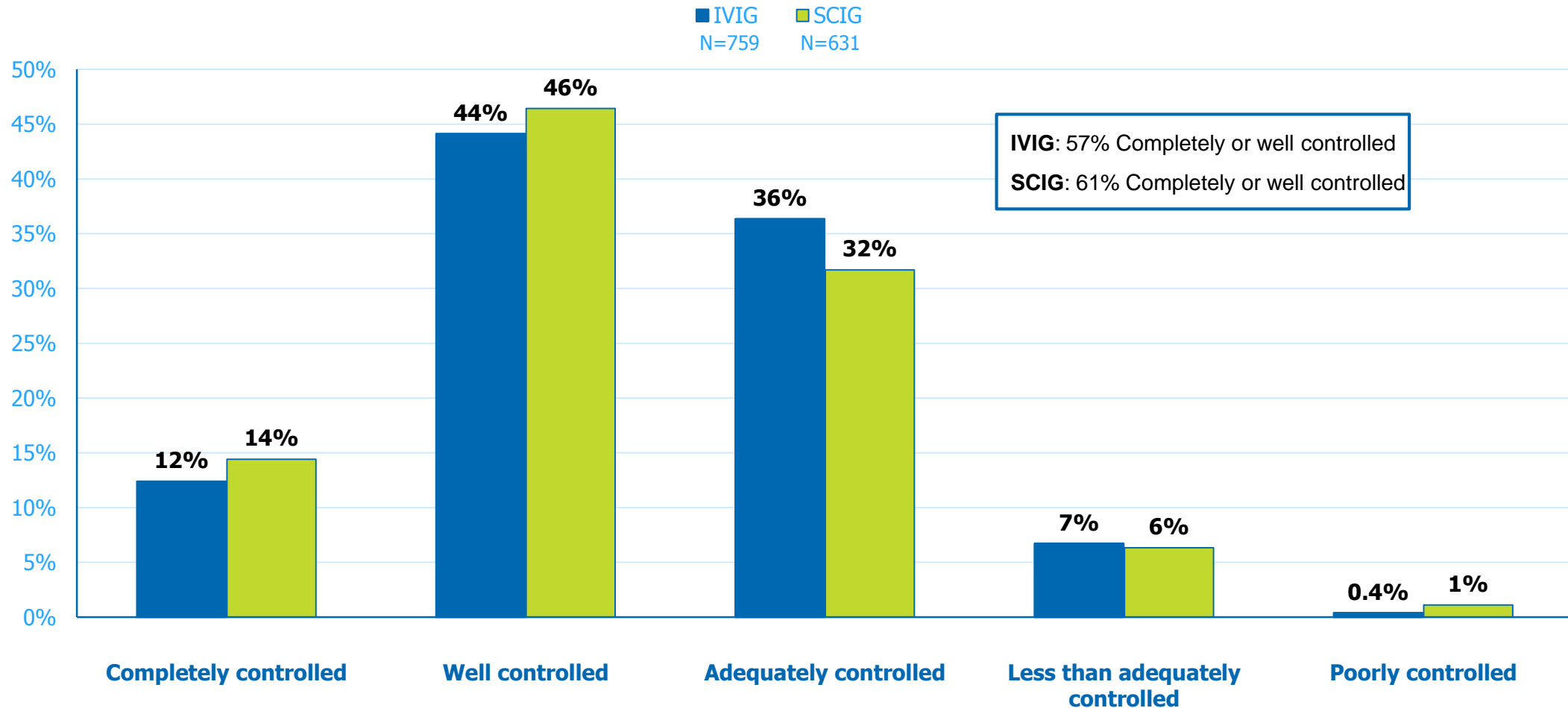
■ Less than 1 week ■ 7 to 21 days ■ 22 to 60 days ■ More than 60 days ■ None



Q41b. How many days in the past 12 months has the patient (parent/caretaker of a patient) missed school or work due to reactions from Ig therapy? N=193
Base: Patients who currently use IVIG or SCIG who missed days from work



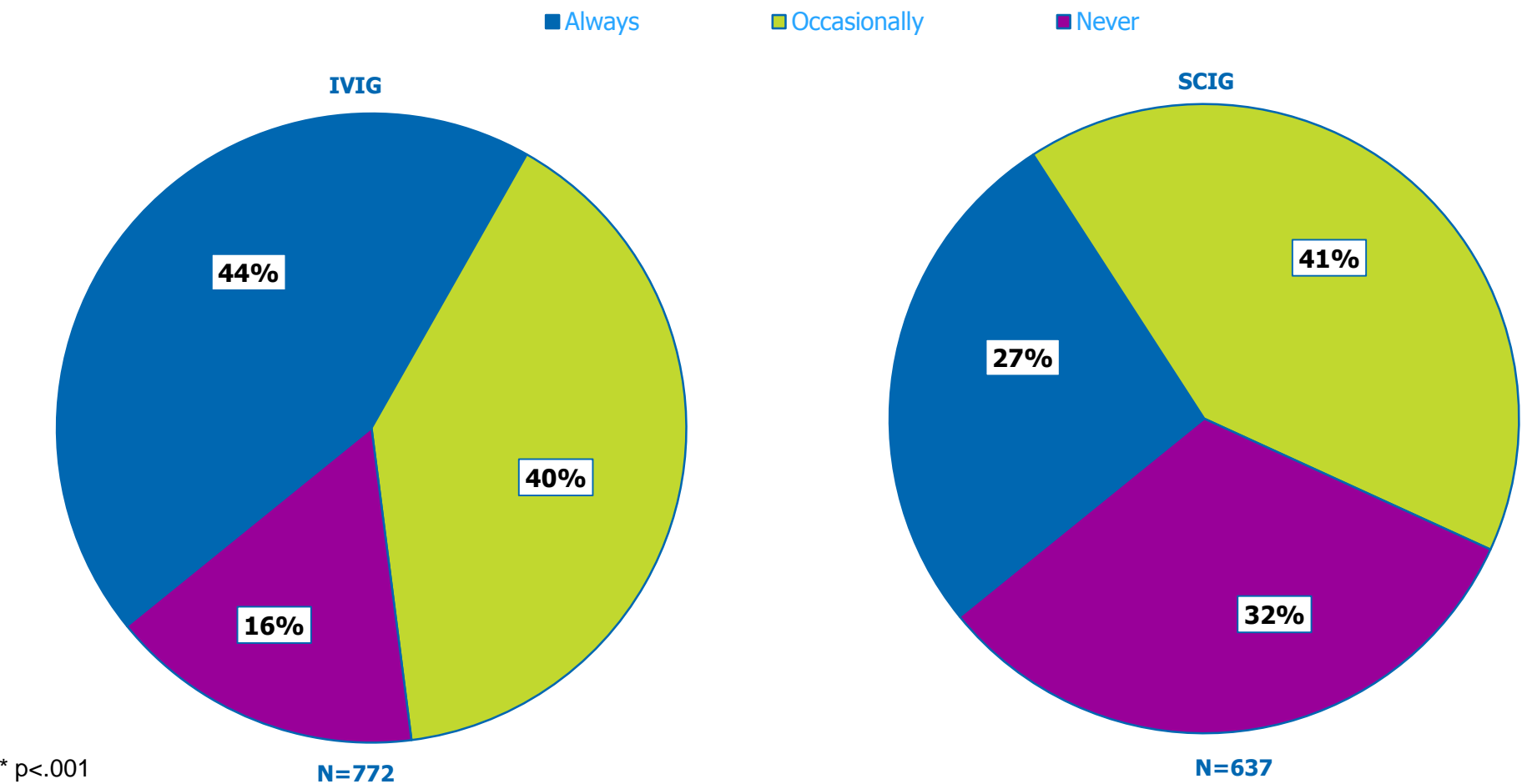
How Well Does Immunoglobulin Control the Patient's Immunodeficiency? IVIG vs. SCIG



Q42. How well does immunoglobulin control the patient's immunodeficiency?
Base: Patients who currently use IVIG or SCIG



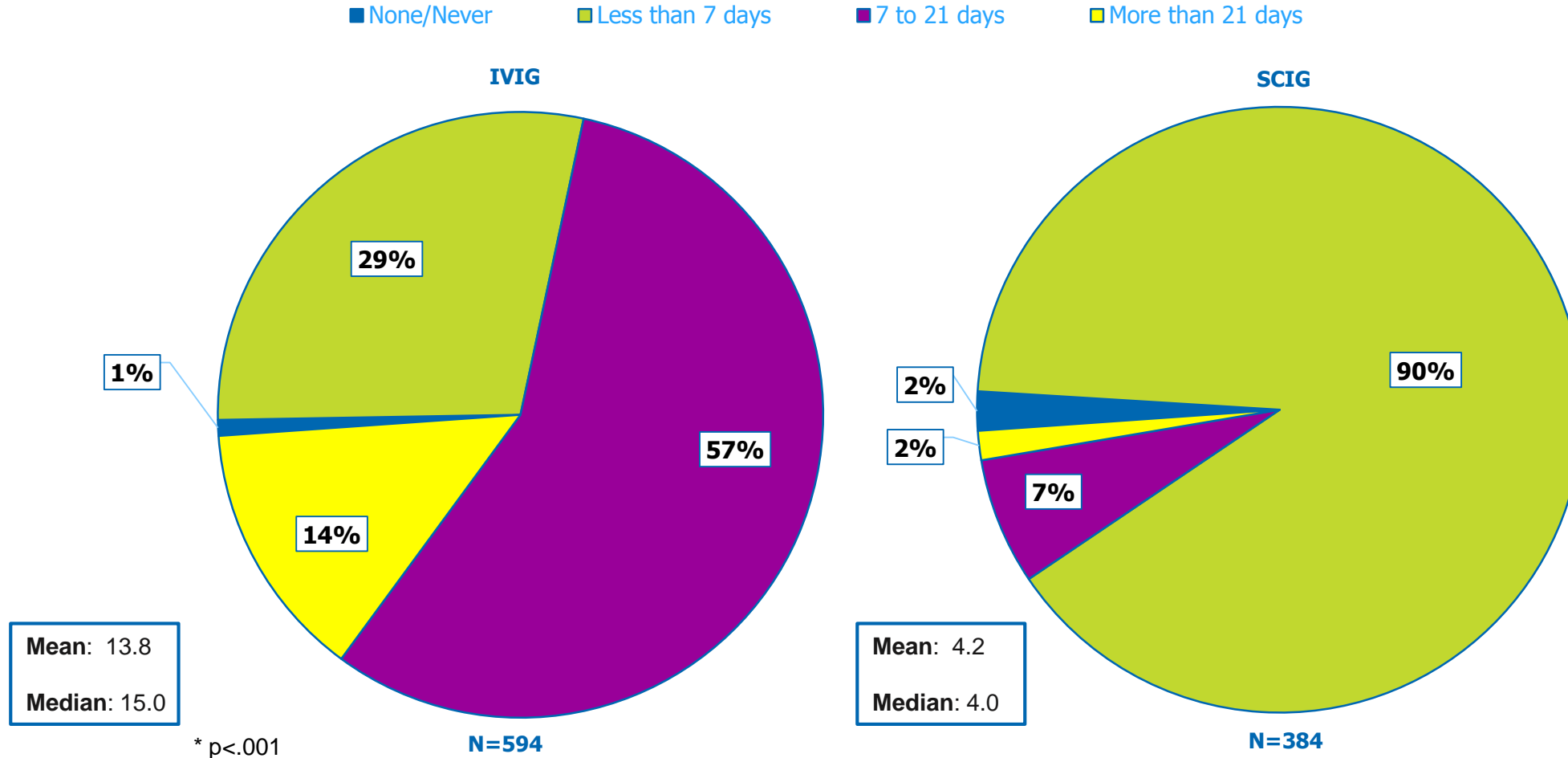
Does the Patient Experience Wear Off Effect? *



Q43a. Does the patient experience periods of fatigue or low energy between Ig therapy treatments (wear off)?
Base: Patients who currently use IVIG or SCIG



How Long After the Infusion Does the Patient Experience the Wear Off Effect? *



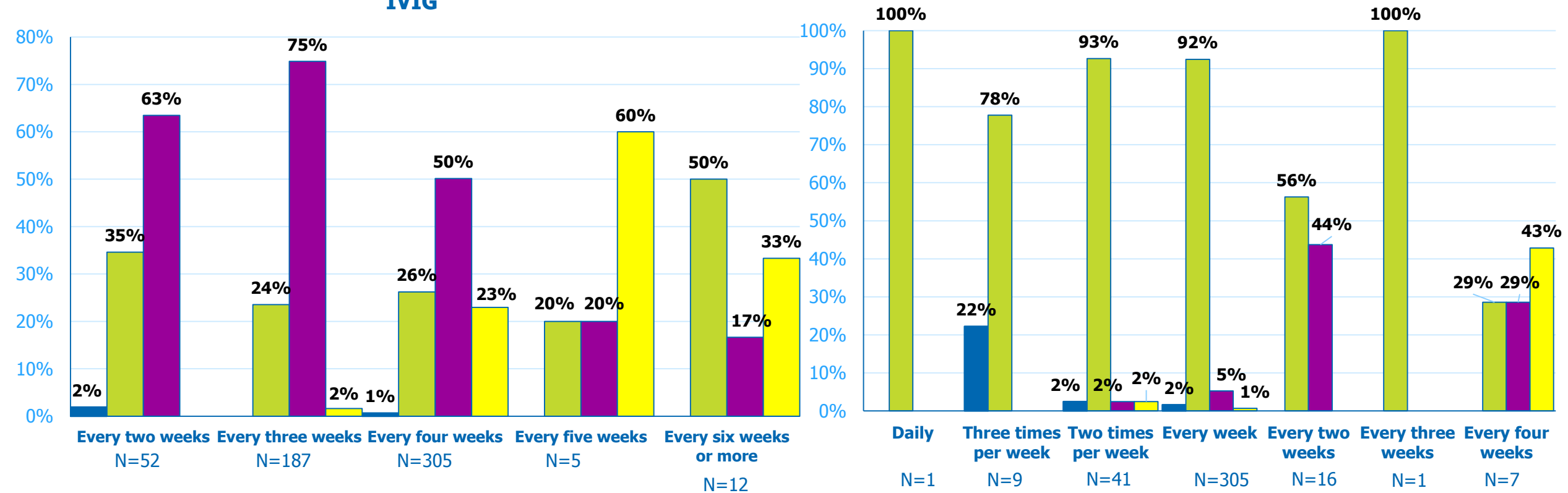
Q43b. How long after infusion does he/she feel this wear off?
Base: Patients who currently use IVIG or SCIG who experience wear off effect

Wear Off Effect by Frequency of Ig Treatment

■ None/Never ■ Less than 7 days ■ 7 to 21 days ■ More than 21 days

IVIG

SCIG

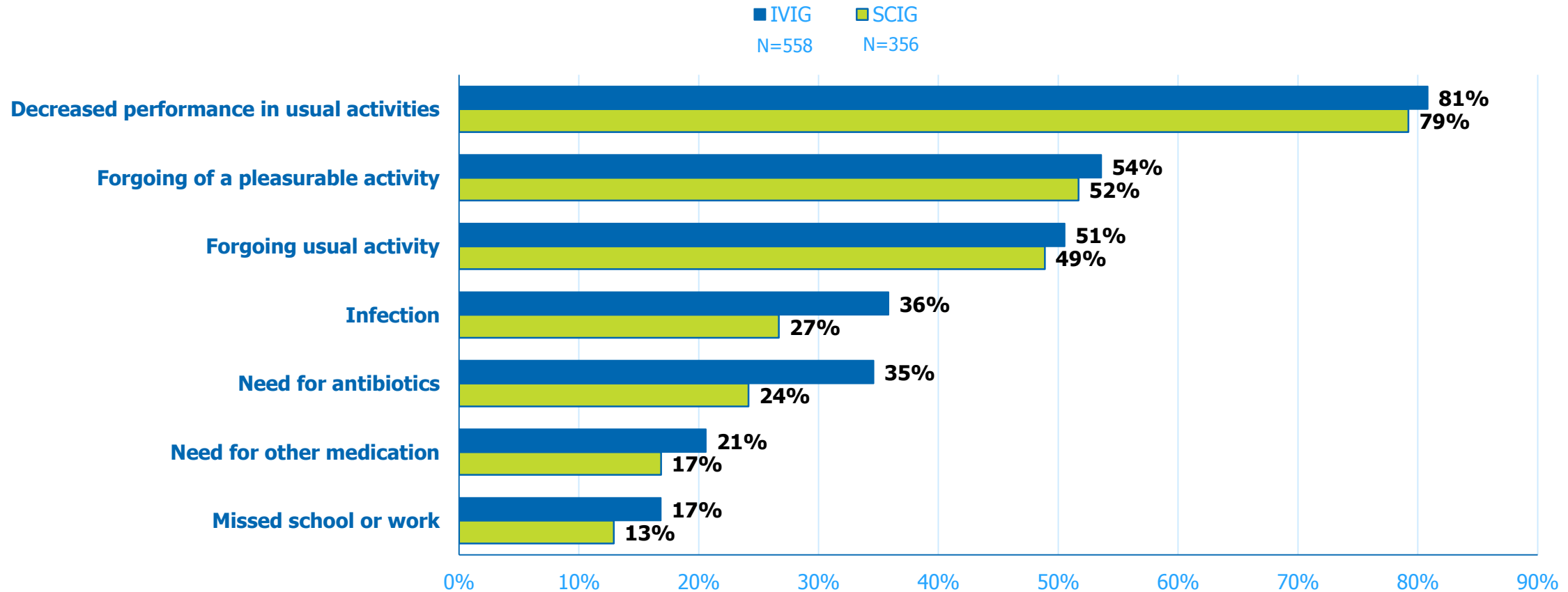


* p<.001

Q30. On average, how often does he/she get their IVIG or SCIG therapy?
Q43b. How long after infusion does he/she feel this wear off?
Base: Patients who currently use IVIG or SCIG who experience wear off effect



The Wear Off Effect Leads to... IVIG vs. SCIG

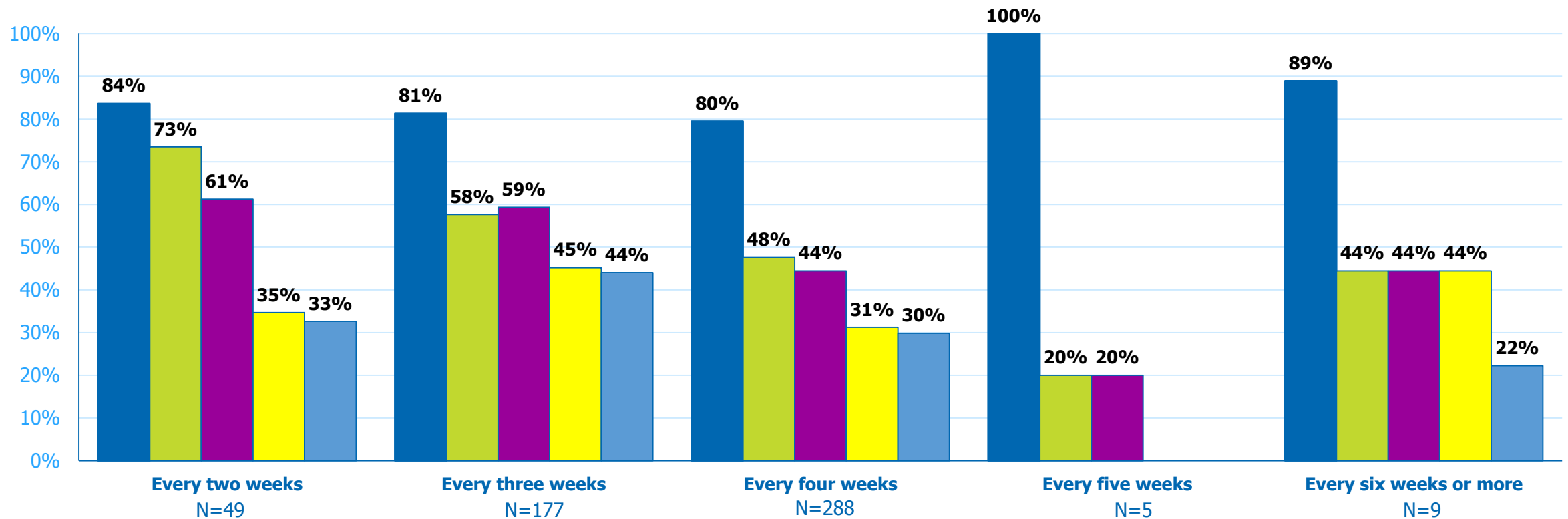


Q43c. Does the "wear off" result in any of the following? SELECT ALL THAT APPLY
Base: Current Ig therapy users who experienced wear off effect



Top 5 Wear Off Effects Side Effects by Frequency of IVIG Treatment

■ Decreased Performance in Usual Activities ■ Forgoing of a Pleasurable Activity ■ Forgoing Usual Activity ■ Infection ■ Need for Antibiotics

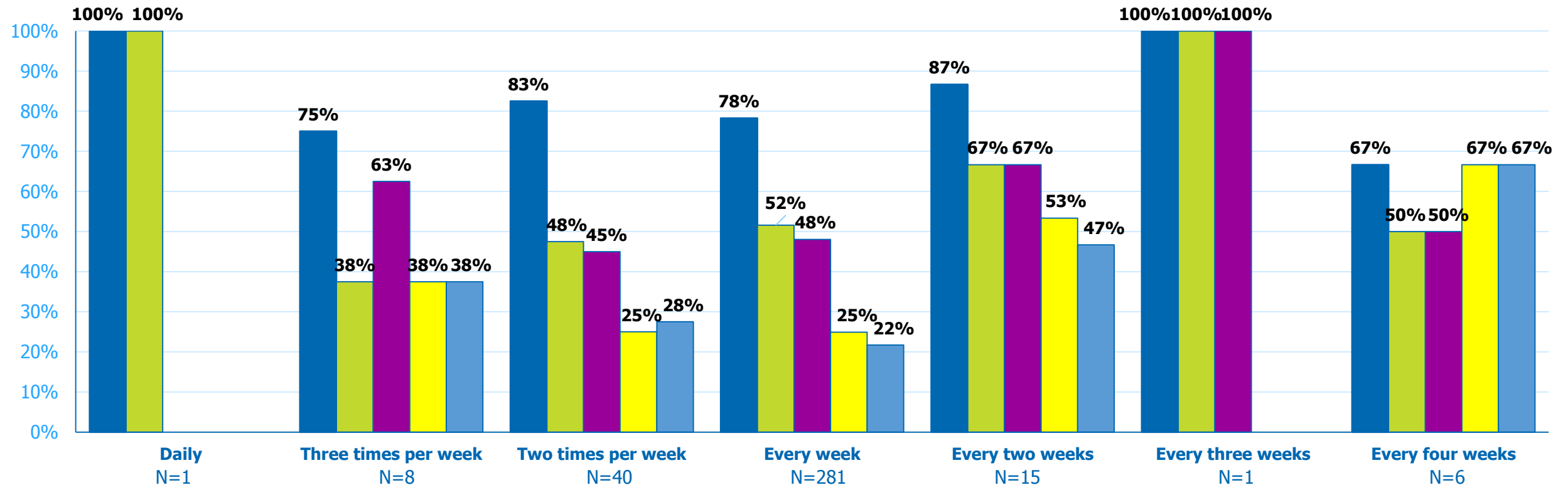


Q30. On average, how often does he/she get their IVIG or SCIG therapy?
Q43c. Does the "wear off" result in any of the following? SELECT ALL THAT APPLY
Base: Patients who currently use IVIG who experience wear off effect



Top 5 Wear Off Effects Side Effects by Frequency of SCIG Treatment

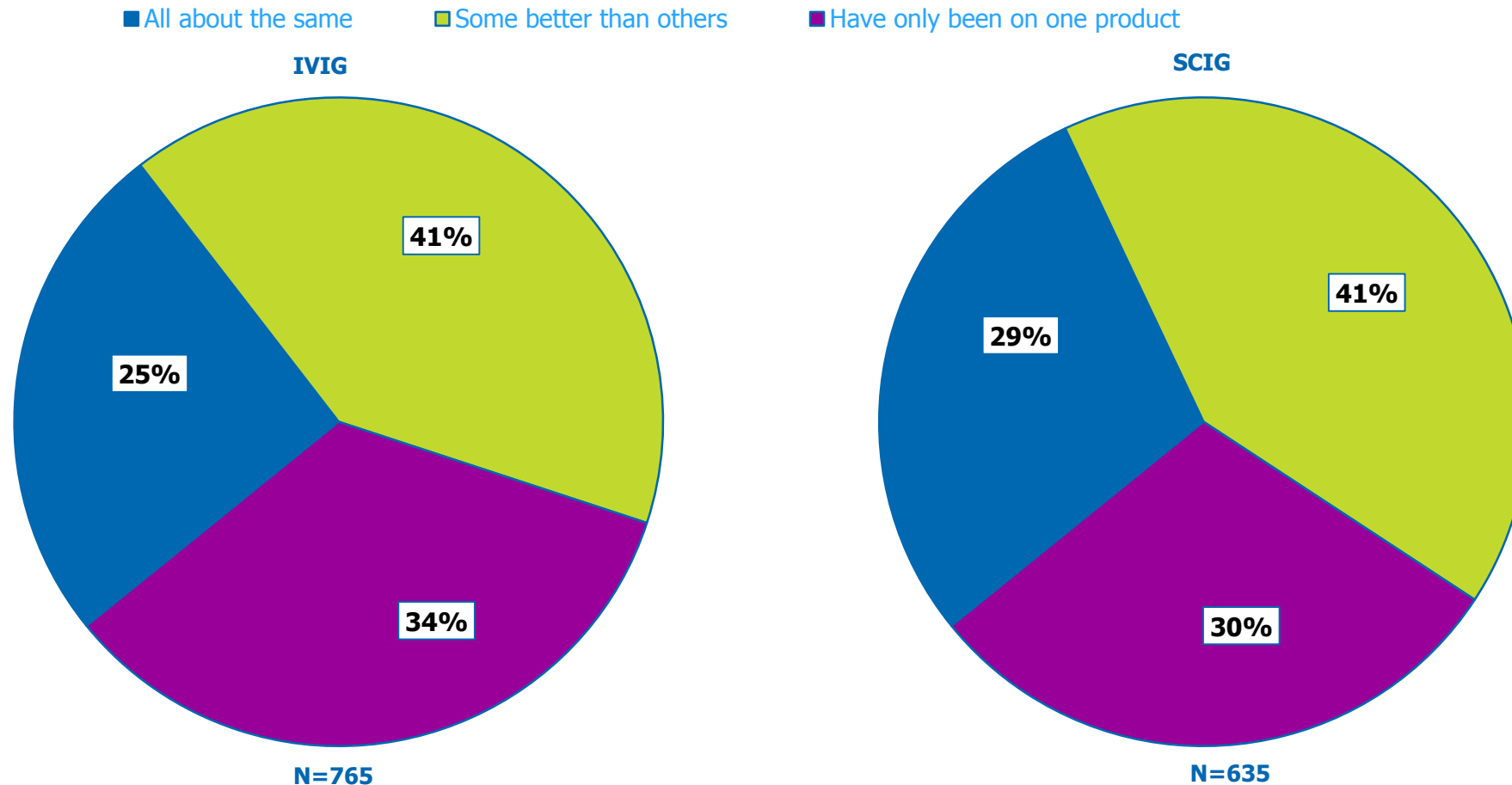
■ Decreased Performance in Usual Activities ■ Forgoing of a Pleasurable Activity ■ Forgoing Usual Activity ■ Infection ■ Need for Antibiotics



Q30. On average, how often does he/she get their IVIG or SCIG therapy?
 Q43c. Does the "wear off" result in any of the following? SELECT ALL THAT APPLY
 Base: Patients who currently use SCIG who experience wear off effect



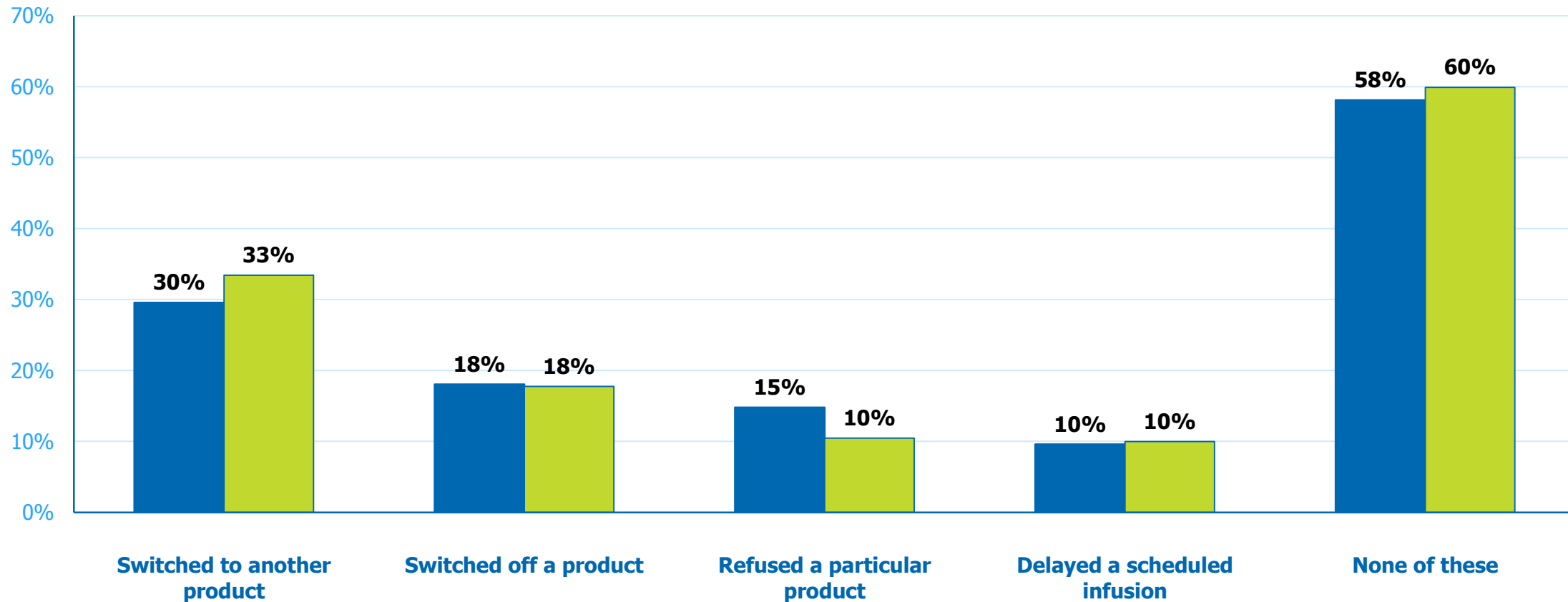
Does the Patient Tolerate Some Ig Products Better Than Others?



Q44. Does he/she tolerate any immunoglobulin products better than others, or are they all about the same?
Base: Patients who currently use IVIG or SCIG

Due to Tolerability Concerns, Patients...

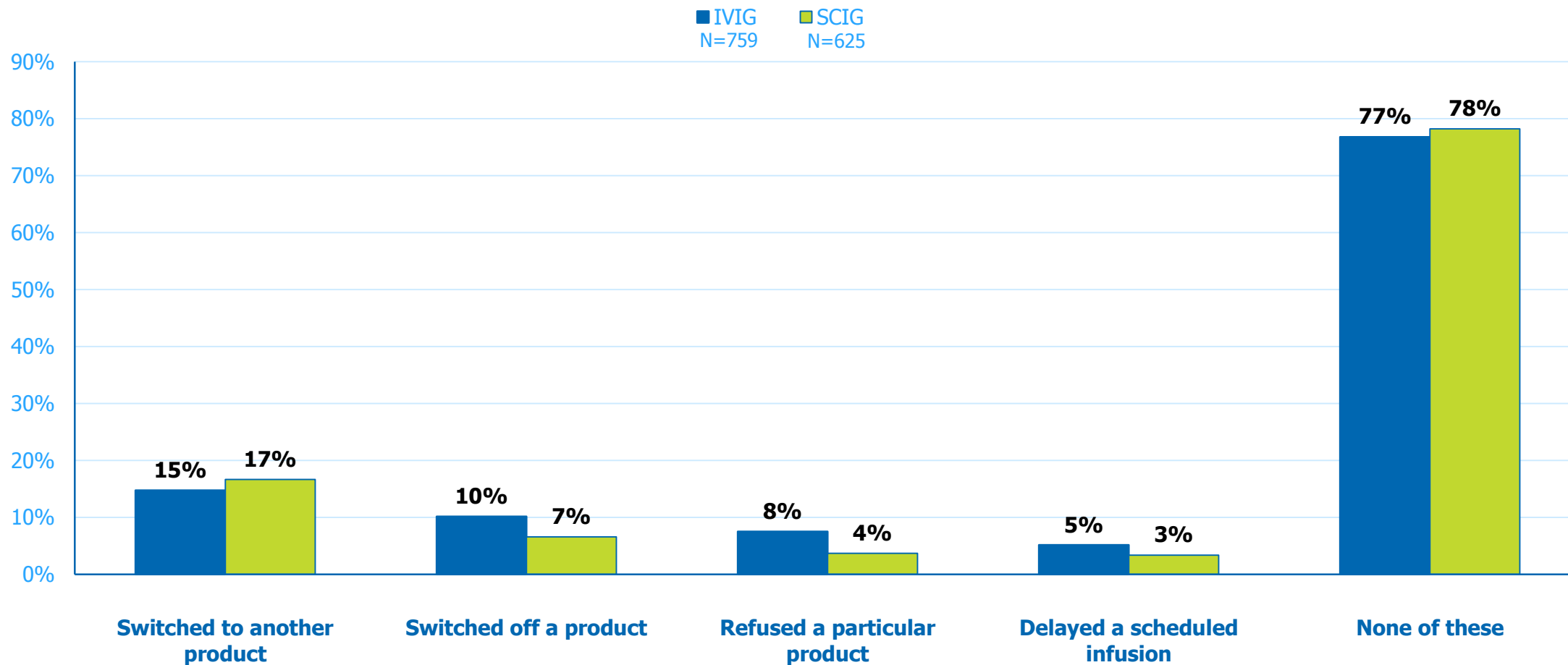
■ IVIG ■ SCIG
N=771 N=631



Q45. As a result of concerns about product tolerability has he/she ever ... SELECT ALL THAT APPLY
Base: Patients who currently use IVIG or SCIG

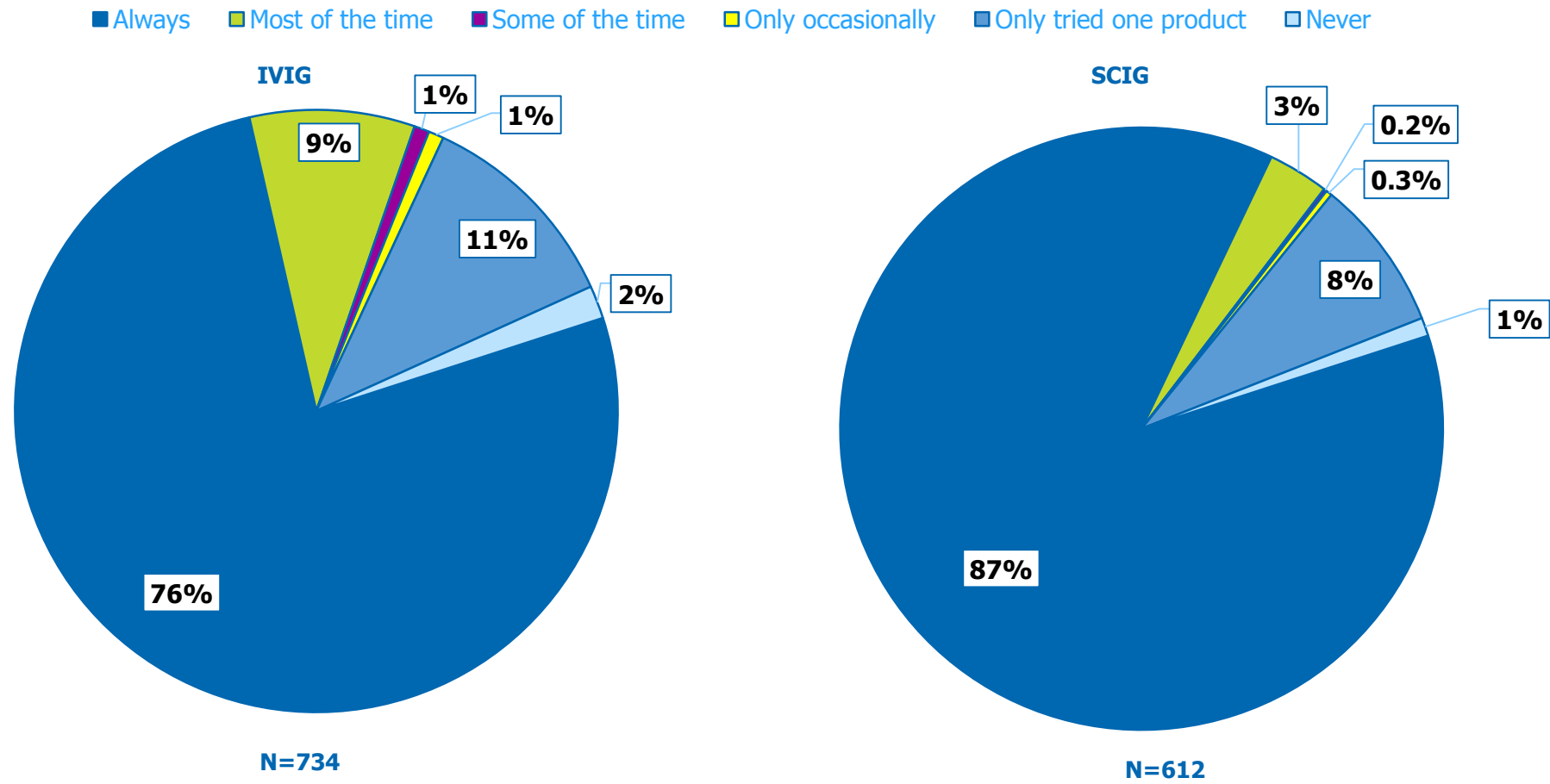


Due to Product Effectiveness, Patients...



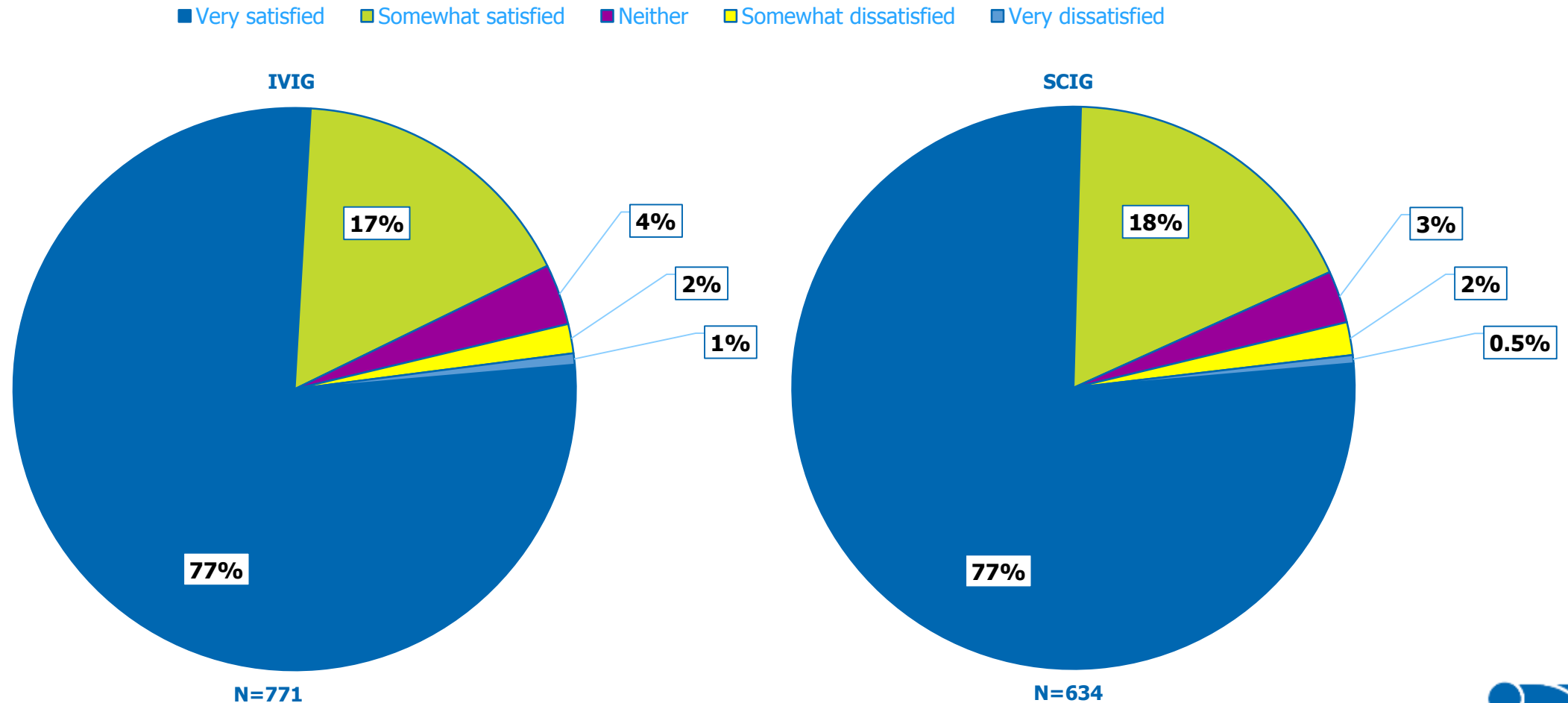
Q46. As a result of product effectiveness has he/she ever ... SELECT ALL THAT APPLY
Base: Patients who currently use IVIG or SCIG

How Often Does the Patient Get Their Preferred Ig Product?



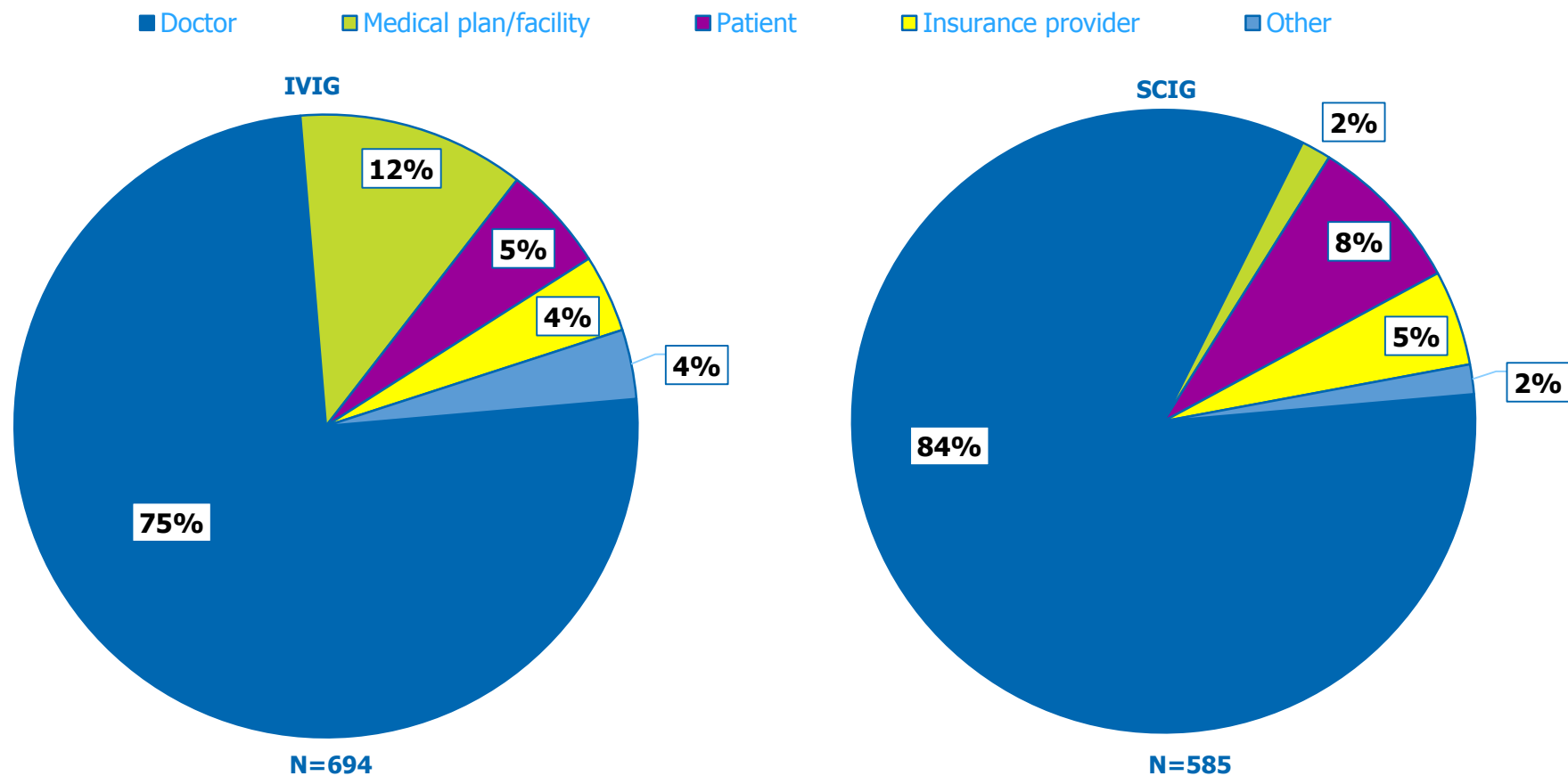
Q48. How often does he/she get the Ig product they prefer most?
Base: Patients who currently use IVIG or SCIG

Satisfaction with Current Ig Product IVIG vs. SCIG



Q49. How satisfied is the patient with the Ig product currently being used?
Base: Patients who currently use IVIG or SCIG

Who Selects the Patient's Ig Product?



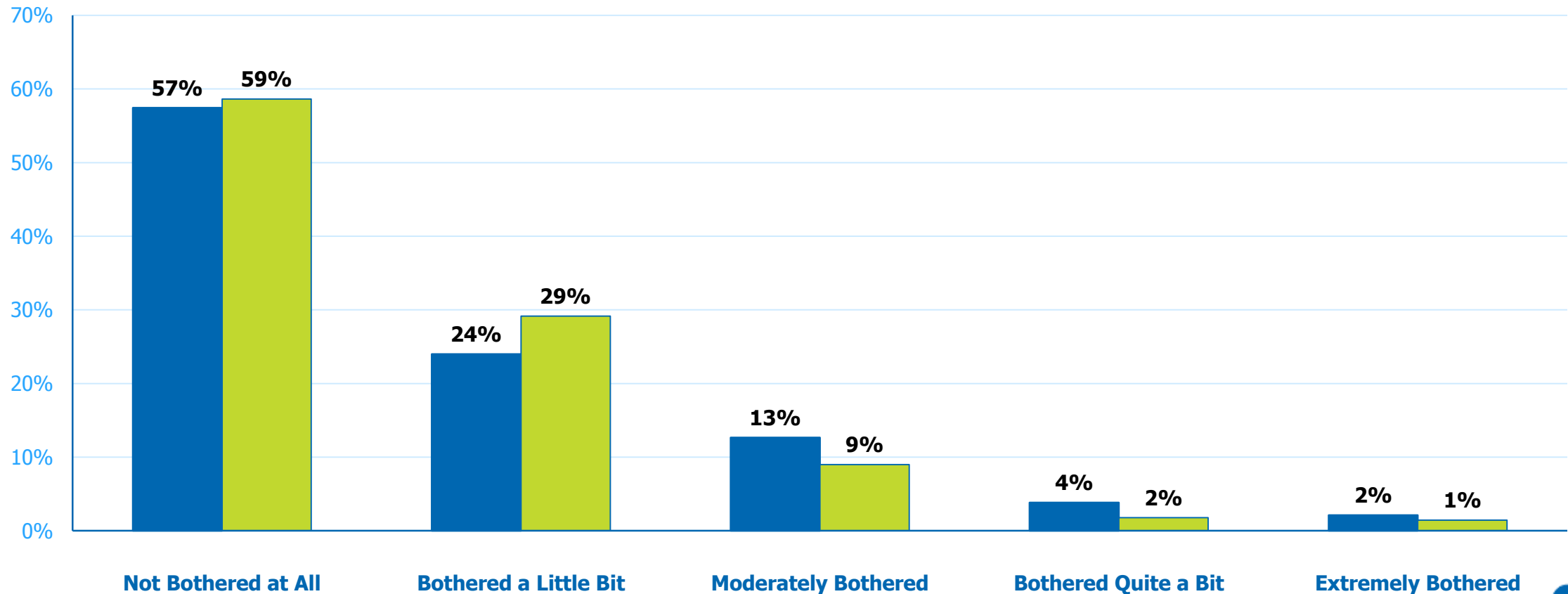
Q50. Who is primarily responsible for the selection of the Ig product that the patient uses?
Base: Patients who currently use IVIG or SCIG



How Much is the Patient Bothered by Convenience of Their Treatment

■ IVIG
N=759

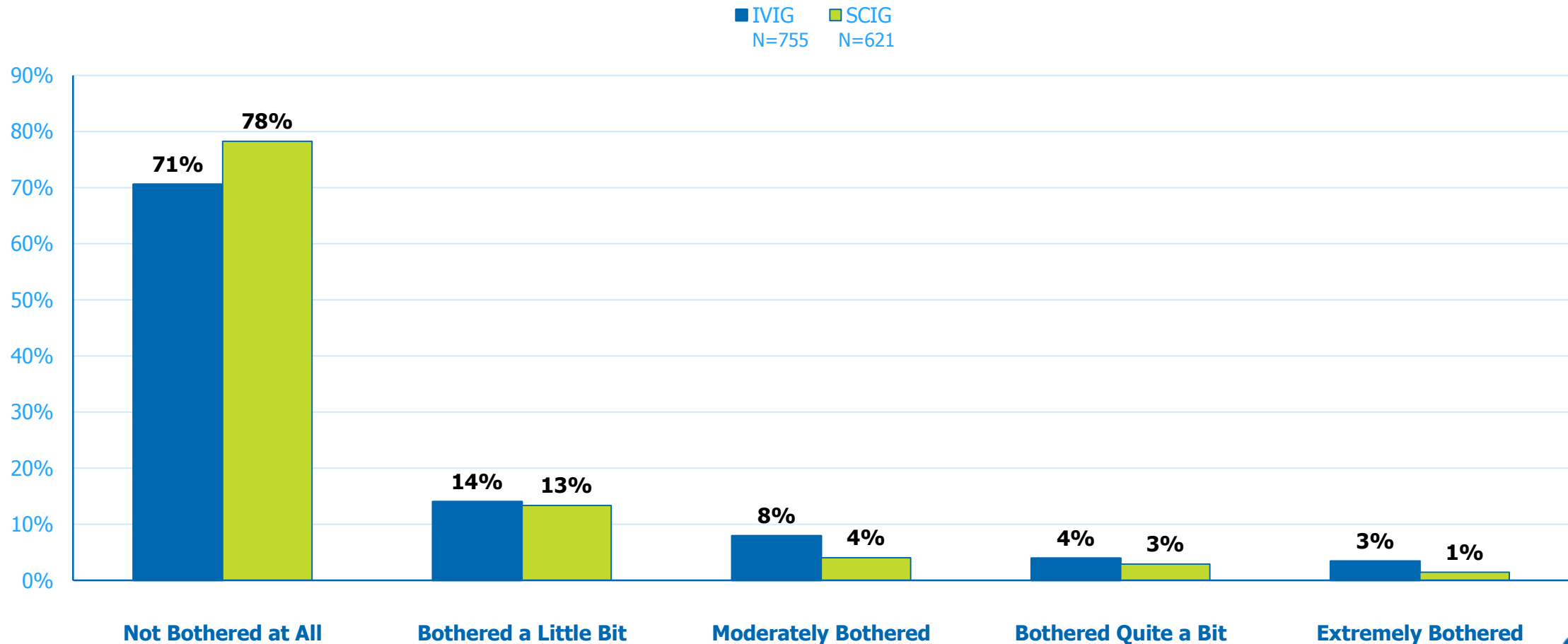
■ SCIG
N=624



Q51A. Thinking about the patient's experience with their CURRENT Ig therapy, please tell us how much the patient is bothered, if at all, by each of the following.
Base: Patients who currently use IVIG or SCIG



How Much is the Patient Bothered by Severe Side-Effects



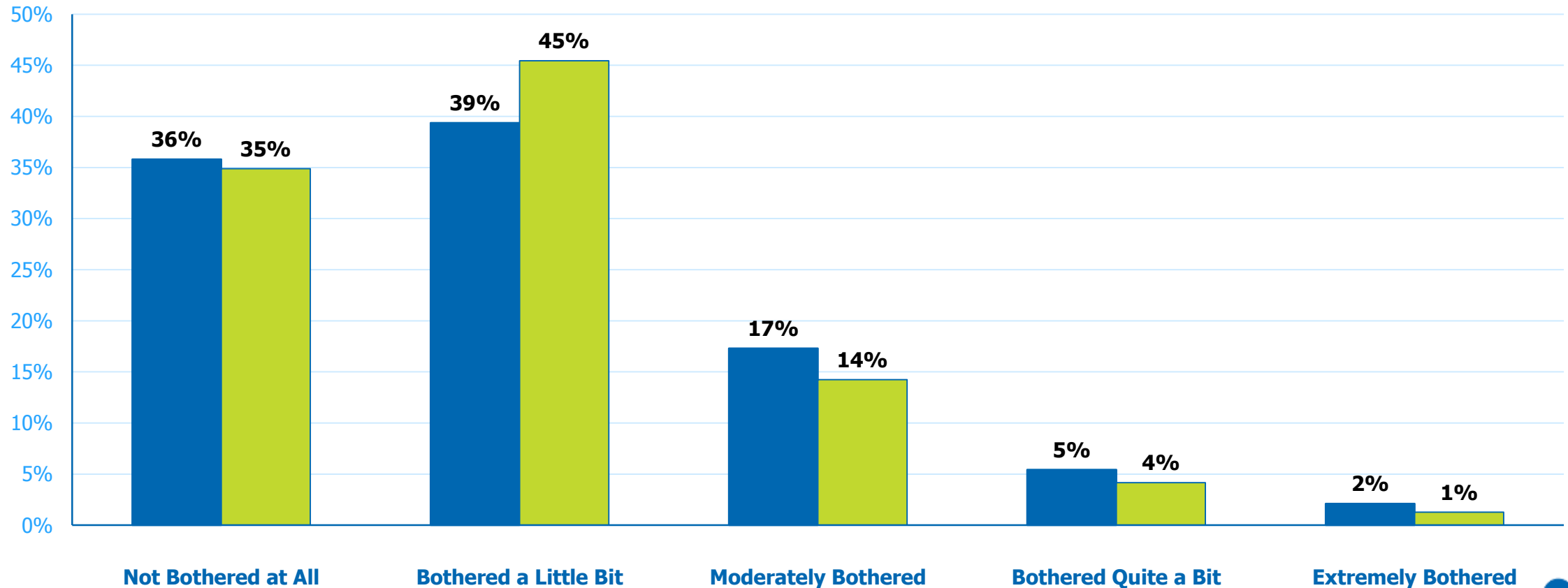
Q51A. Thinking about the patient's experience with their CURRENT Ig therapy, please tell us how much the patient is bothered, if at all, by each of the following.
Base: Patients who currently use IVIG or SCIG



How Much is the Patient Bothered by Minor Side-Effects

■ IVIG
N=757

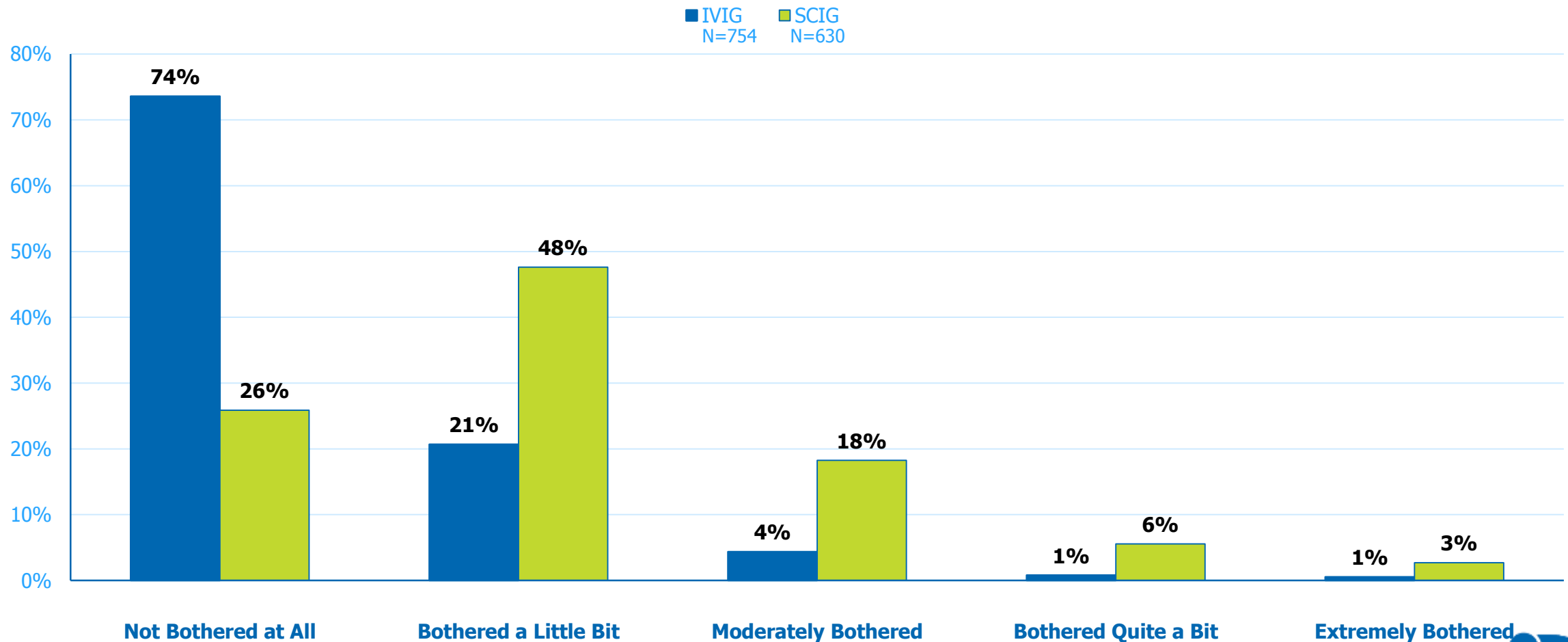
■ SCIG
N=625



Q51A. Thinking about the patient's experience with their CURRENT Ig therapy, please tell us how much the patient is bothered, if at all, by each of the following.
Base: Patients who currently use IVIG or SCIG



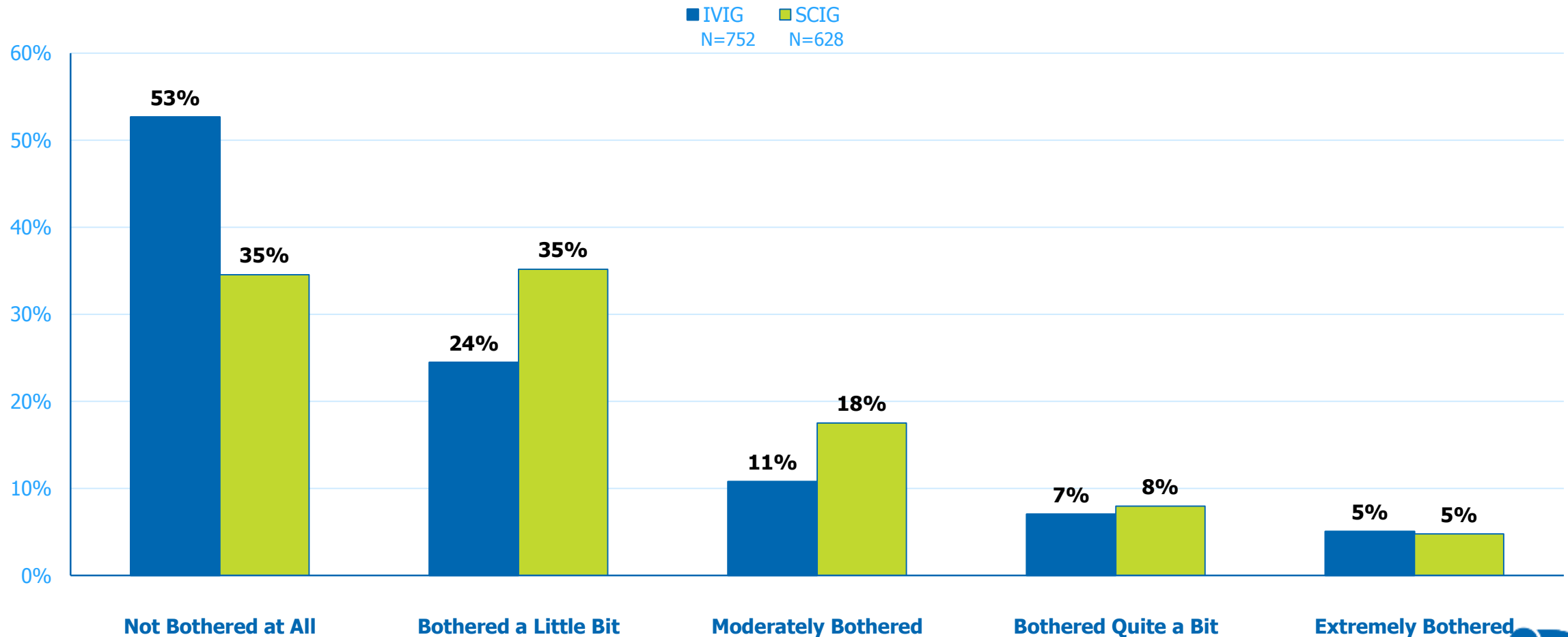
How Much is the Patient Bothered by Local Site Reactions



Q51A. Thinking about the patient's experience with their CURRENT Ig therapy, please tell us how much the patient is bothered, if at all, by each of the following.
Base: Patients who currently use IVIG or SCIG



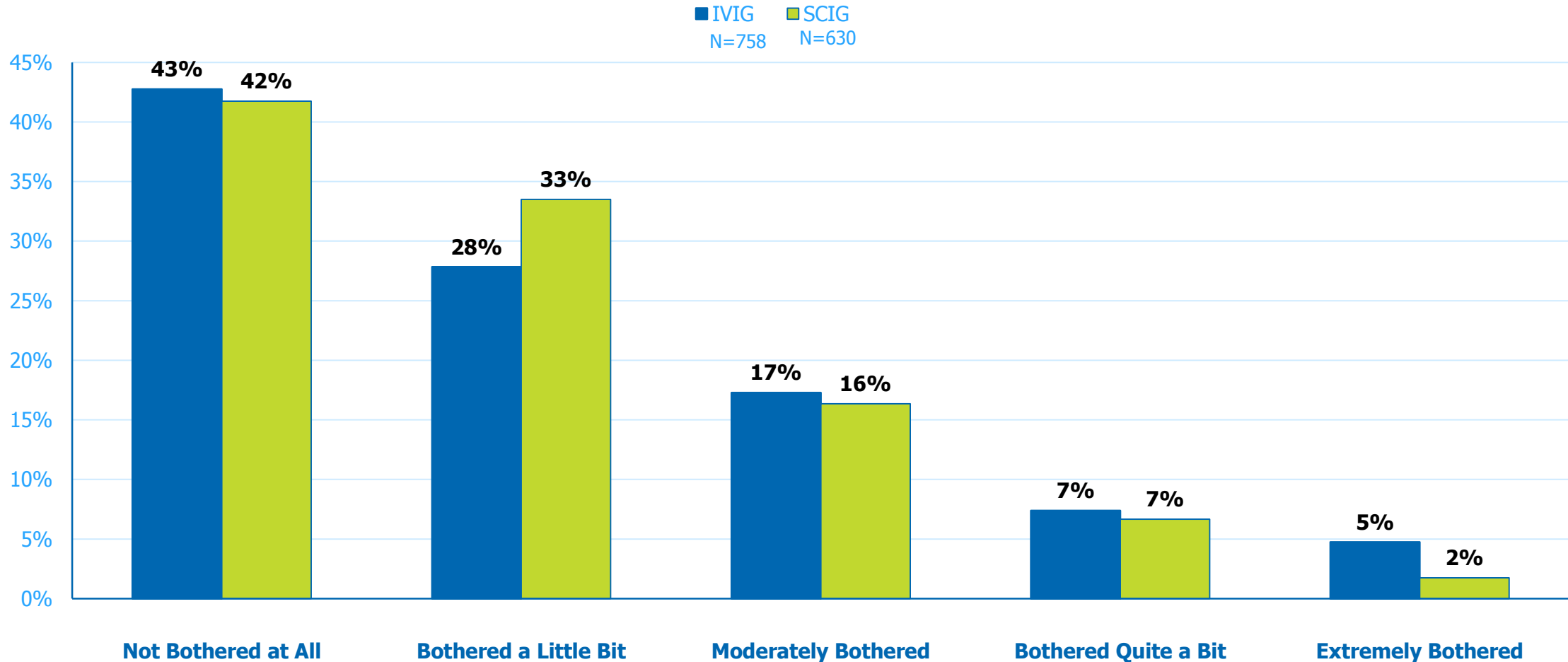
How Much is the Patient Bothered by Number of Needle Sticks



Q51A. Thinking about the patient's experience with their CURRENT Ig therapy, please tell us how much the patient is bothered, if at all, by each of the following.
Base: Patients who currently use IVIG or SCIG



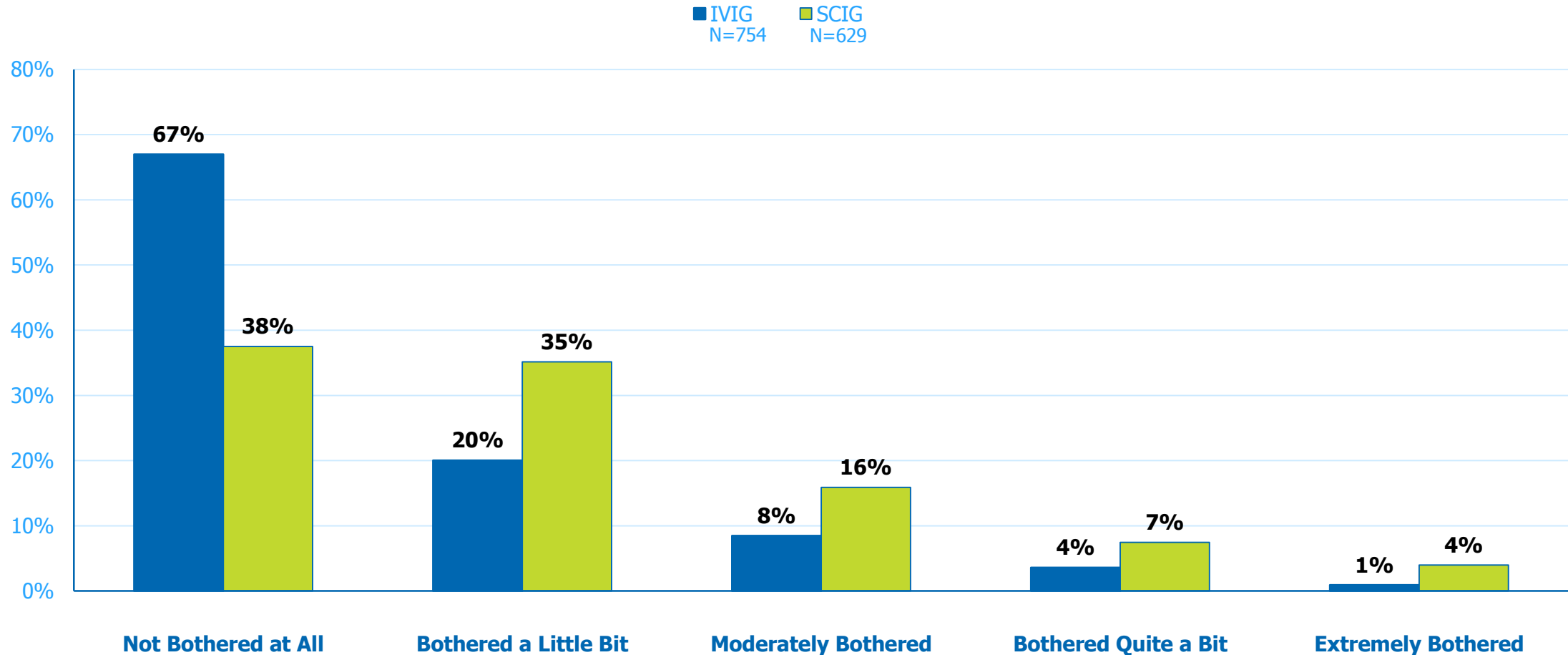
How Much is the Patient Bothered by Time to Infuse



Q51A. Thinking about the patient's experience with their CURRENT Ig therapy, please tell us how much the patient is bothered, if at all, by each of the following.
Base: Patients who currently use IVIG or SCIG



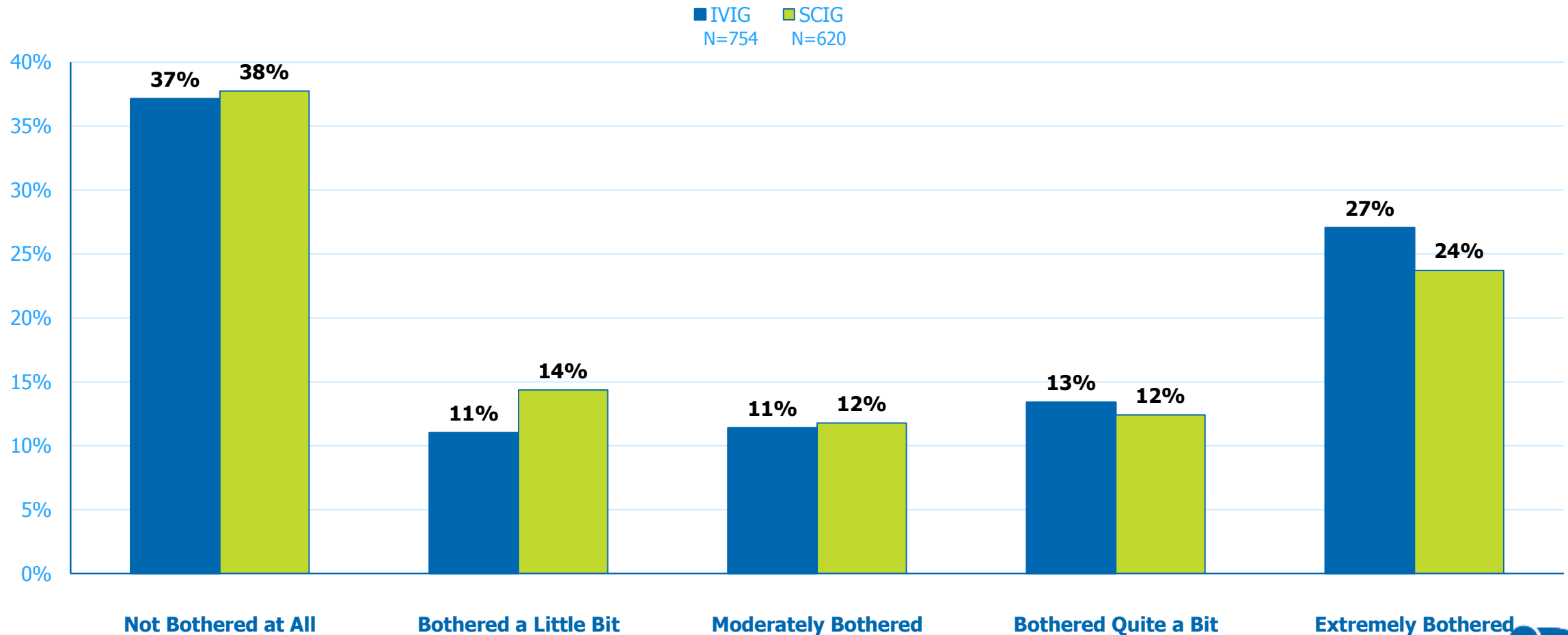
How Much is the Patient Bothered by Number of Infusions Each Month



Q51A. Thinking about the patient's experience with their CURRENT Ig therapy, please tell us how much the patient is bothered, if at all, by each of the following.
Base: Patients who currently use IVIG or SCIG



How Much is the Patient Bothered by Cost of Infusions

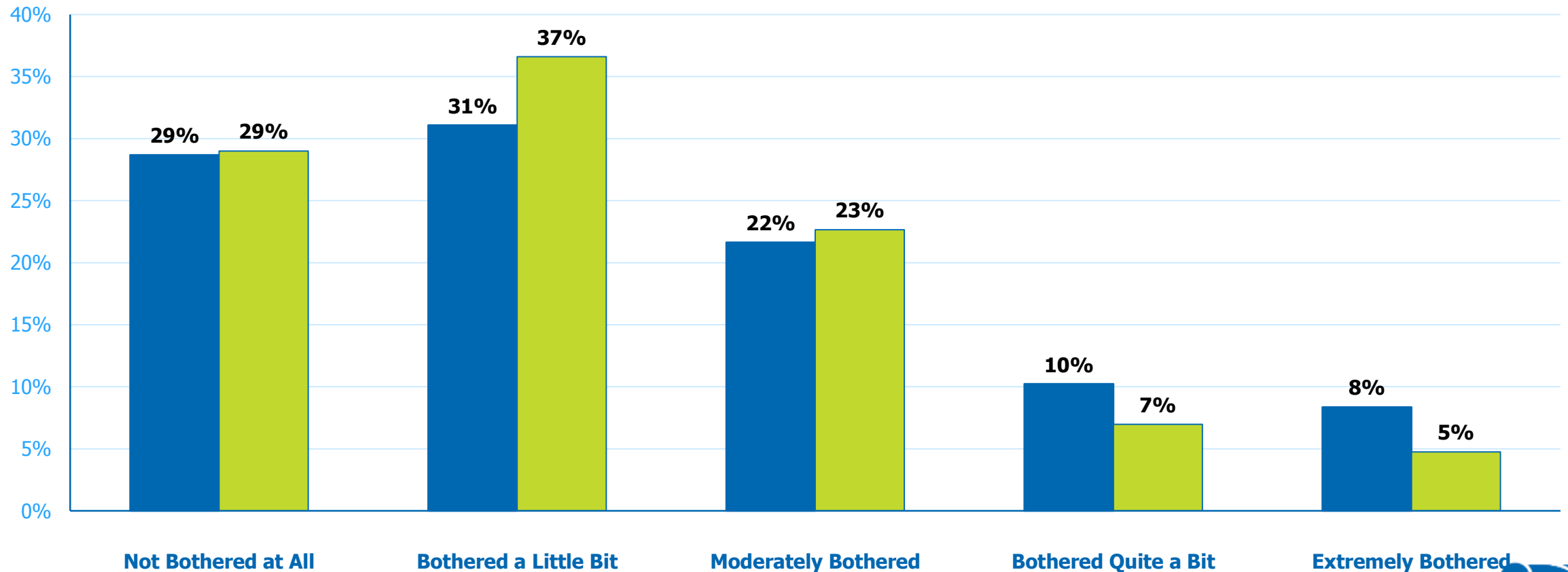


Q51A. Thinking about the patient's experience with their CURRENT Ig therapy, please tell us how much the patient is bothered, if at all, by each of the following.
Base: Patients who currently use IVIG or SCIG



How Much is the Patient Bothered by Interrupts Life

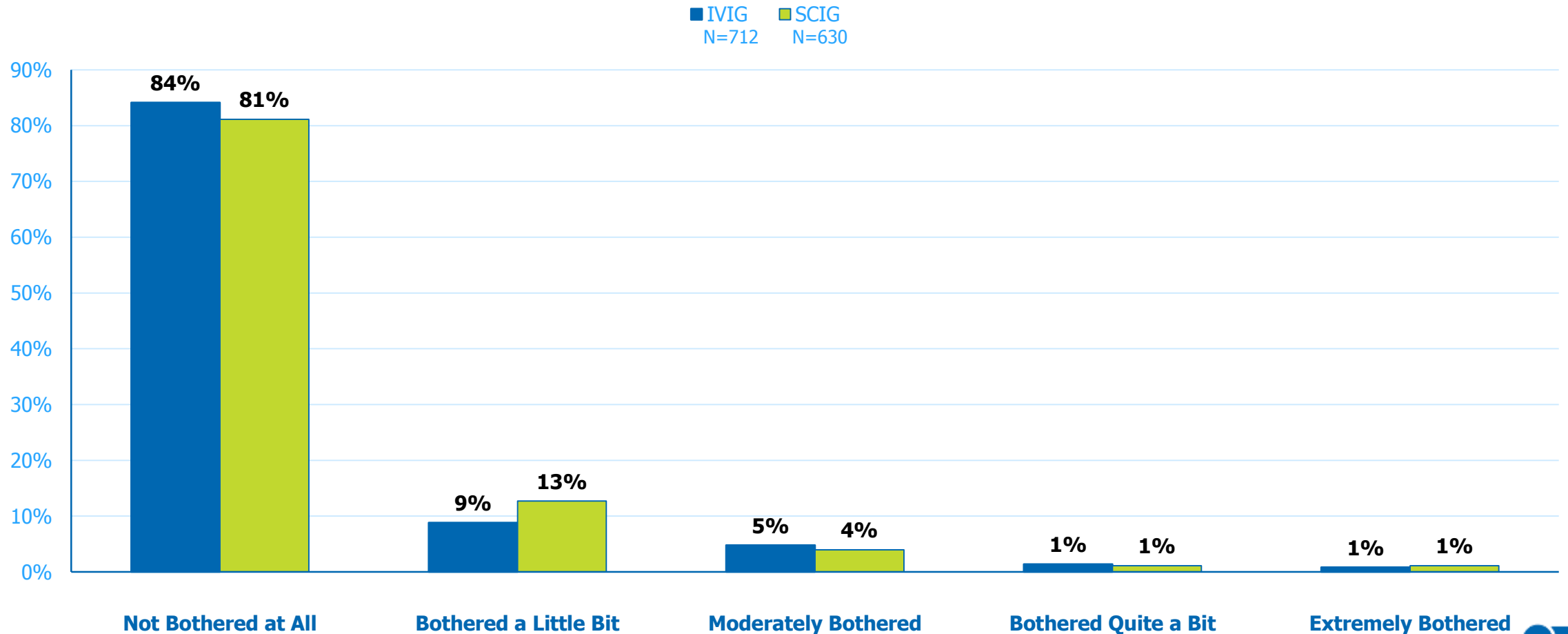
■ IVIG N=753
■ SCIG N=631



Q51A. Thinking about the patient's experience with their CURRENT Ig therapy, please tell us how much the patient is bothered, if at all, by each of the following.
Base: Patients who currently use IVIG or SCIG



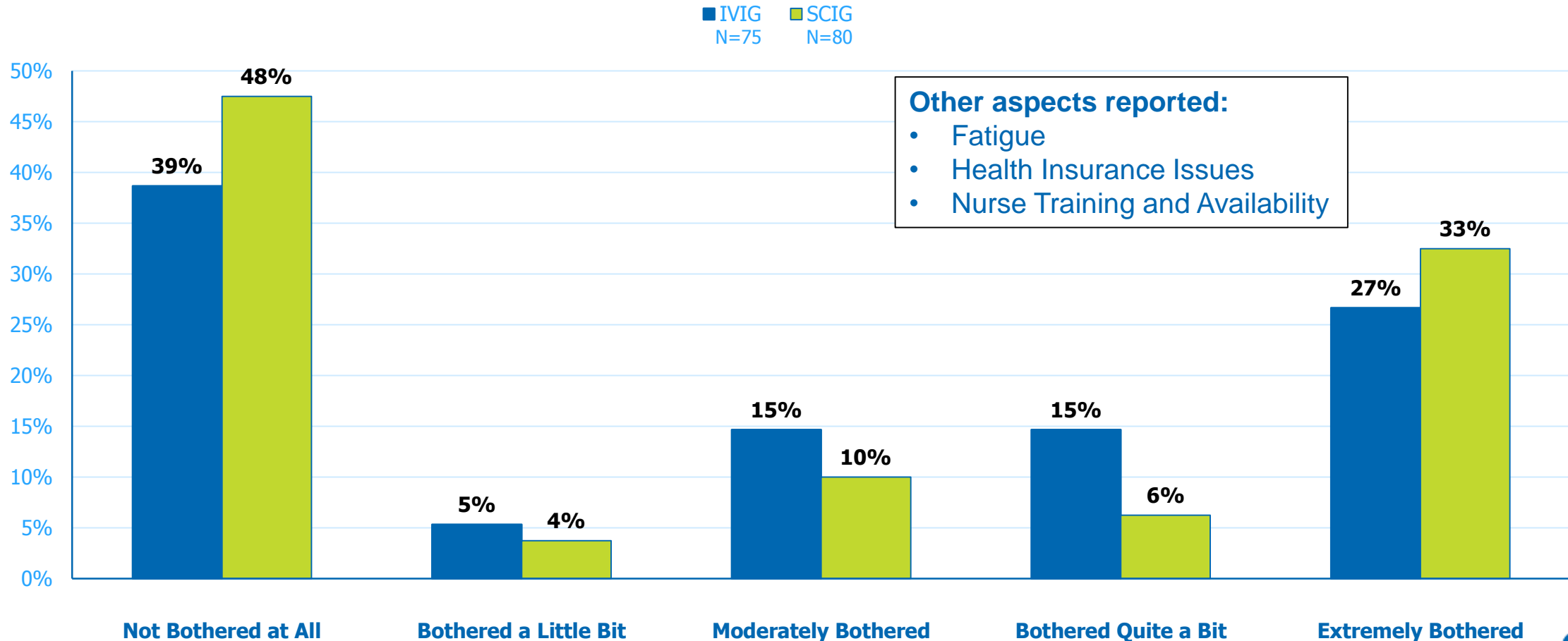
How Much is the Patient Bothered by Operating Pump or Infusion Device



Q51A. Thinking about the patient's experience with their CURRENT Ig therapy, please tell us how much the patient is bothered, if at all, by each of the following.
Base: Patients who currently use IVIG or SCIG



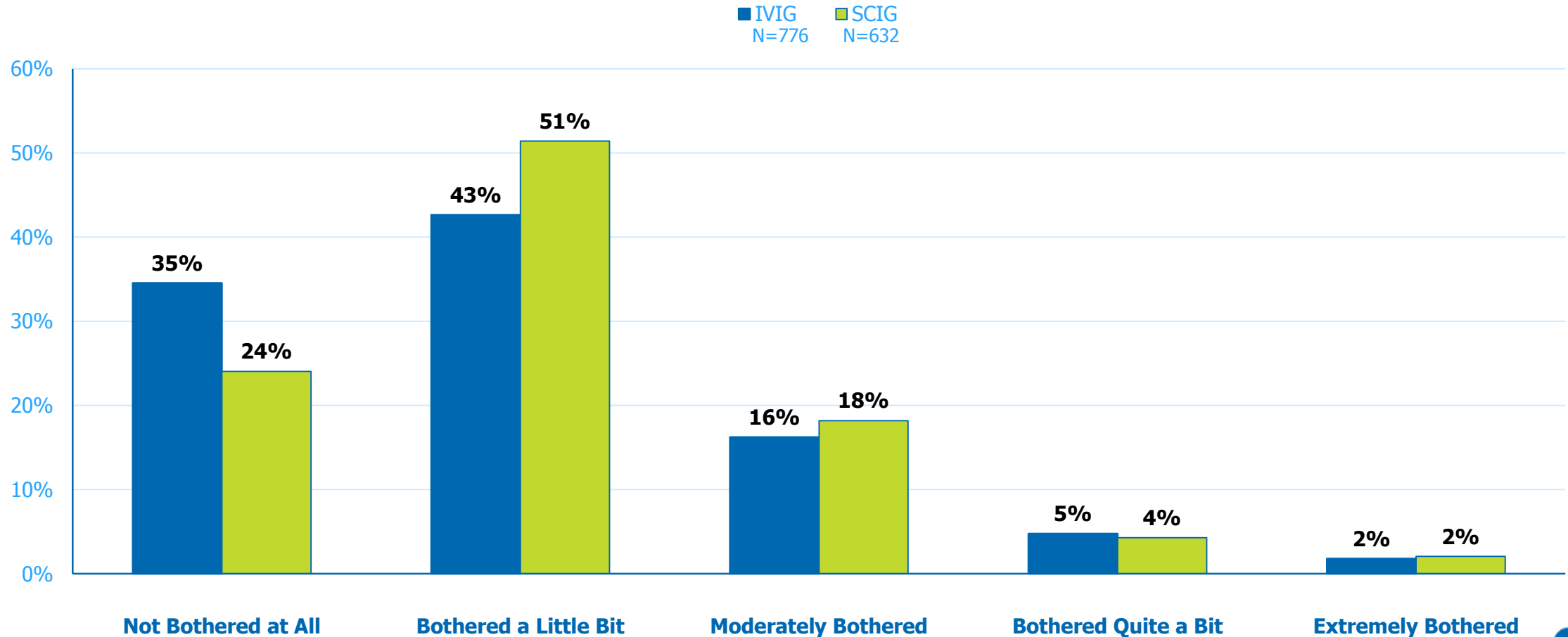
How Much is the Patient Bothered by Other Aspects of Ig Therapy



Q51A. Thinking about the patient's experience with their CURRENT Ig therapy, please tell us how much the patient is bothered, if at all, by each of the following. Base: Patients who currently use IVIG or SCIG



How Much is the Patient Bothered by Ig Therapy Overall

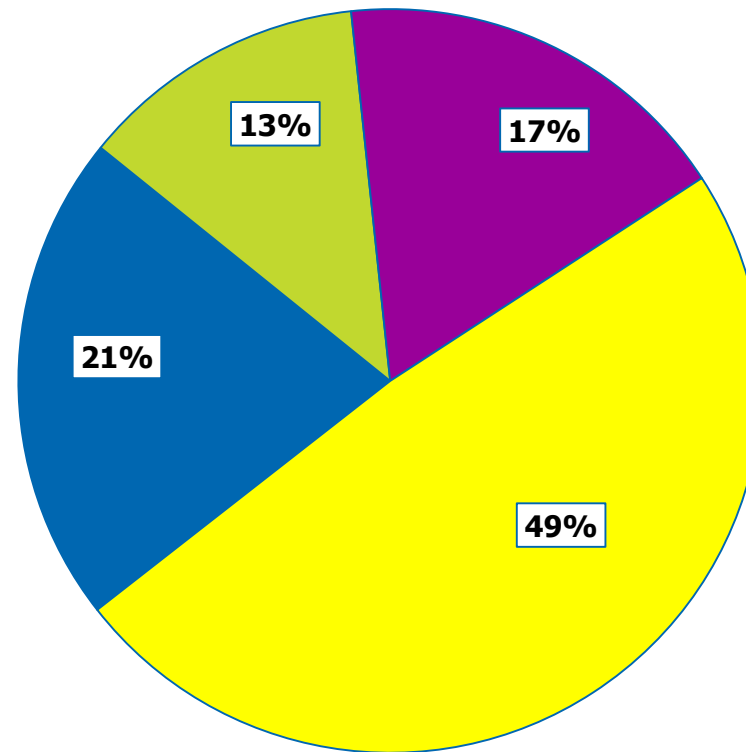


Q51B. Overall, how bothered is the patient when they get Ig Therapy?
Base: Patients who currently use IVIG or SCIG



Prophylactic Antibiotic Therapy

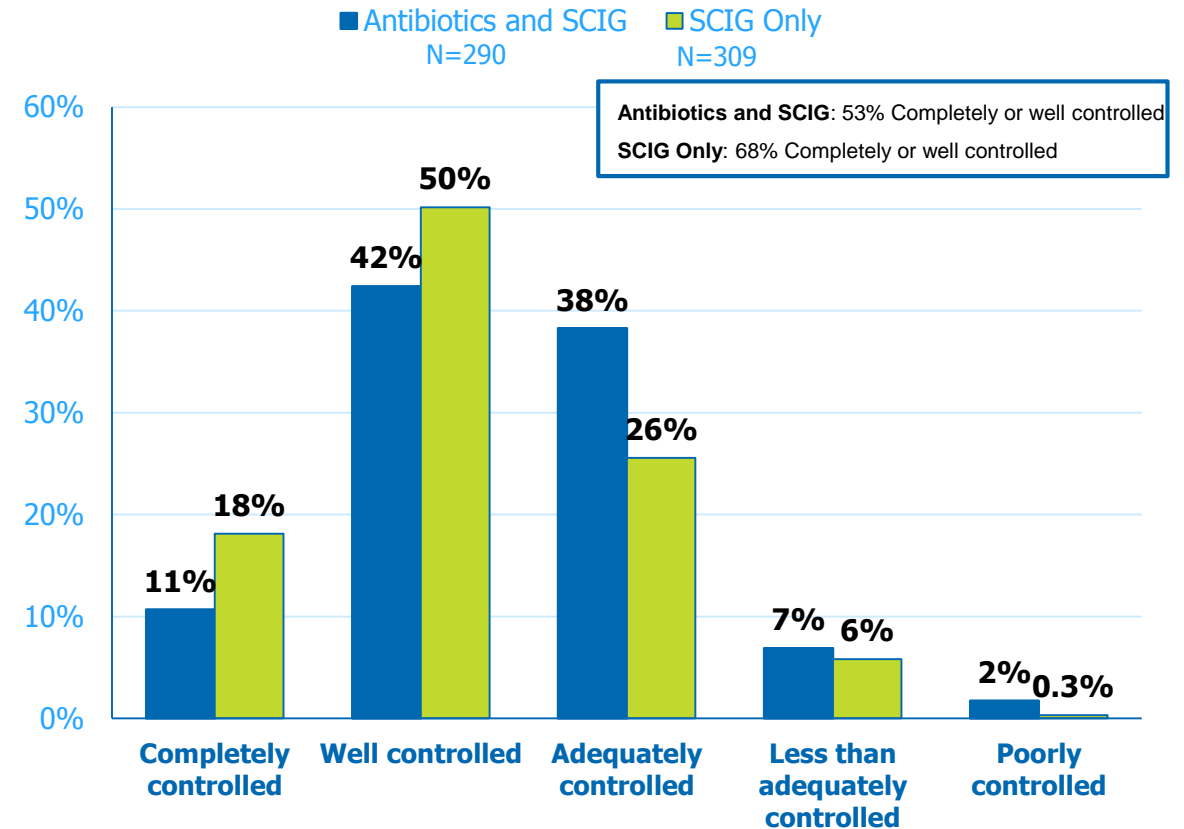
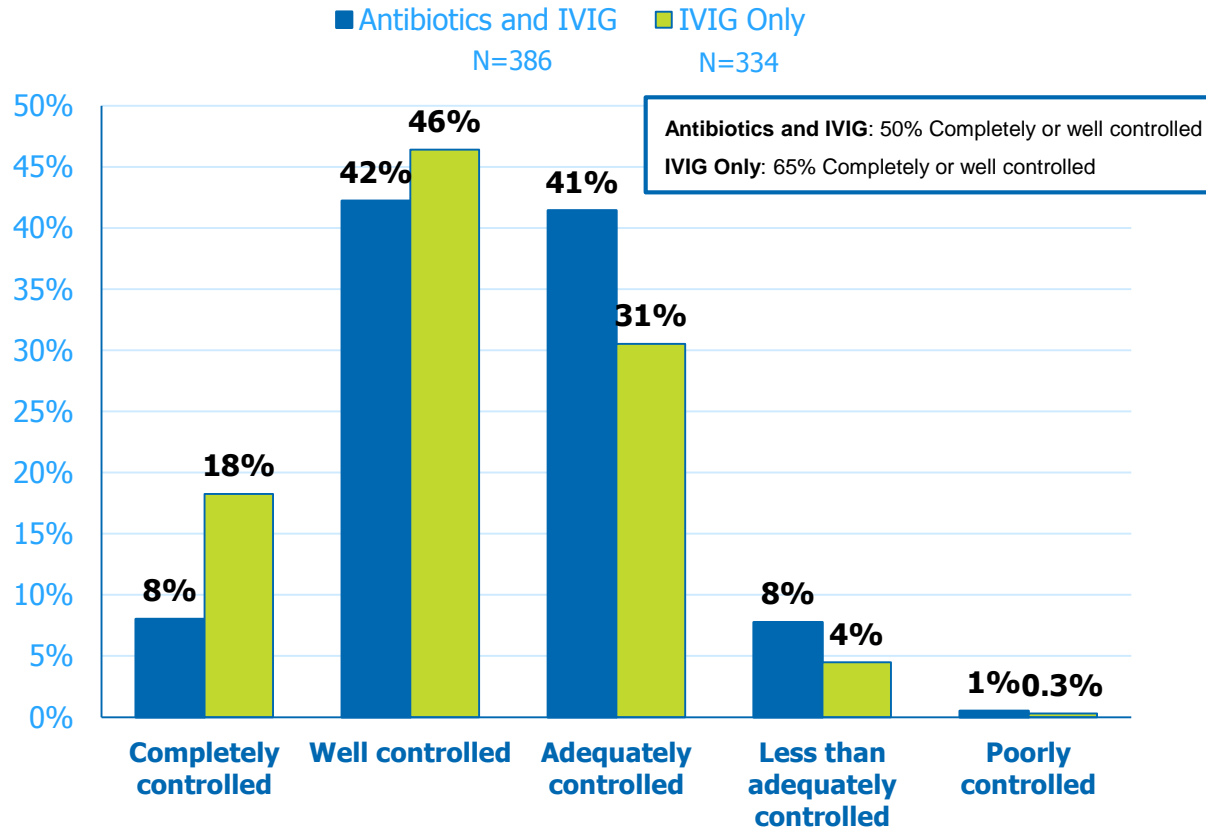
■ Less than 1 month ■ 1 to 6 months ■ Longer than 6 months ■ Did not take any antibiotics



Q61. In the past 12 months, how long has the patient taken antibiotics to prevent infections (prophylactically)? N=1,349
Base: Patients who currently use IVIG or SCIG



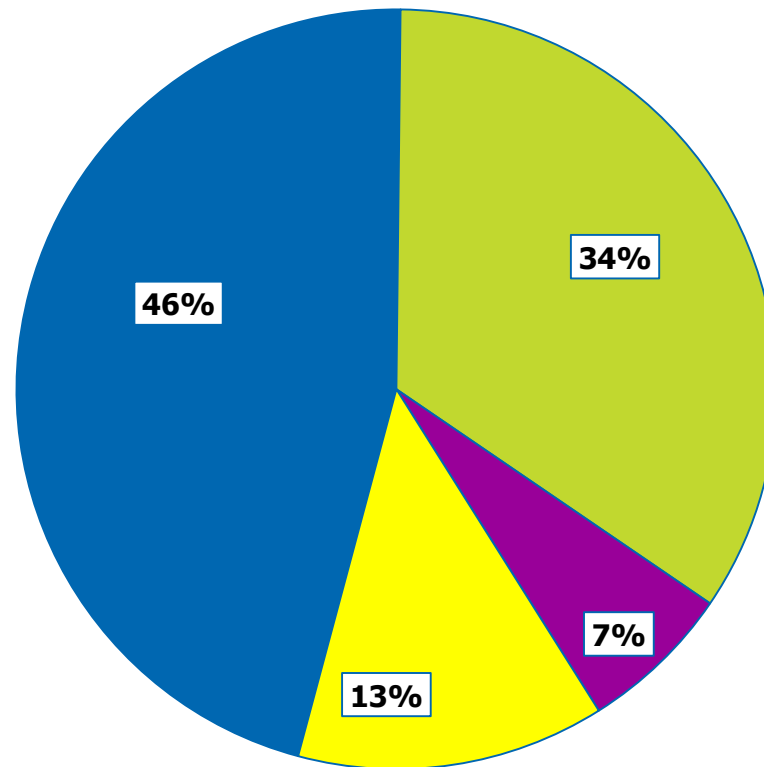
Prophylactic Antibiotic Therapy by Ig Therapy



Q42. How well does immunoglobulin control the patient's immunodeficiency?
Q61. In the past 12 months, how long has the patient taken antibiotics to prevent infections (prophylactically)?
Base: Patients who currently use IVIG or SCIG

Antibiotics to Treat an Infection

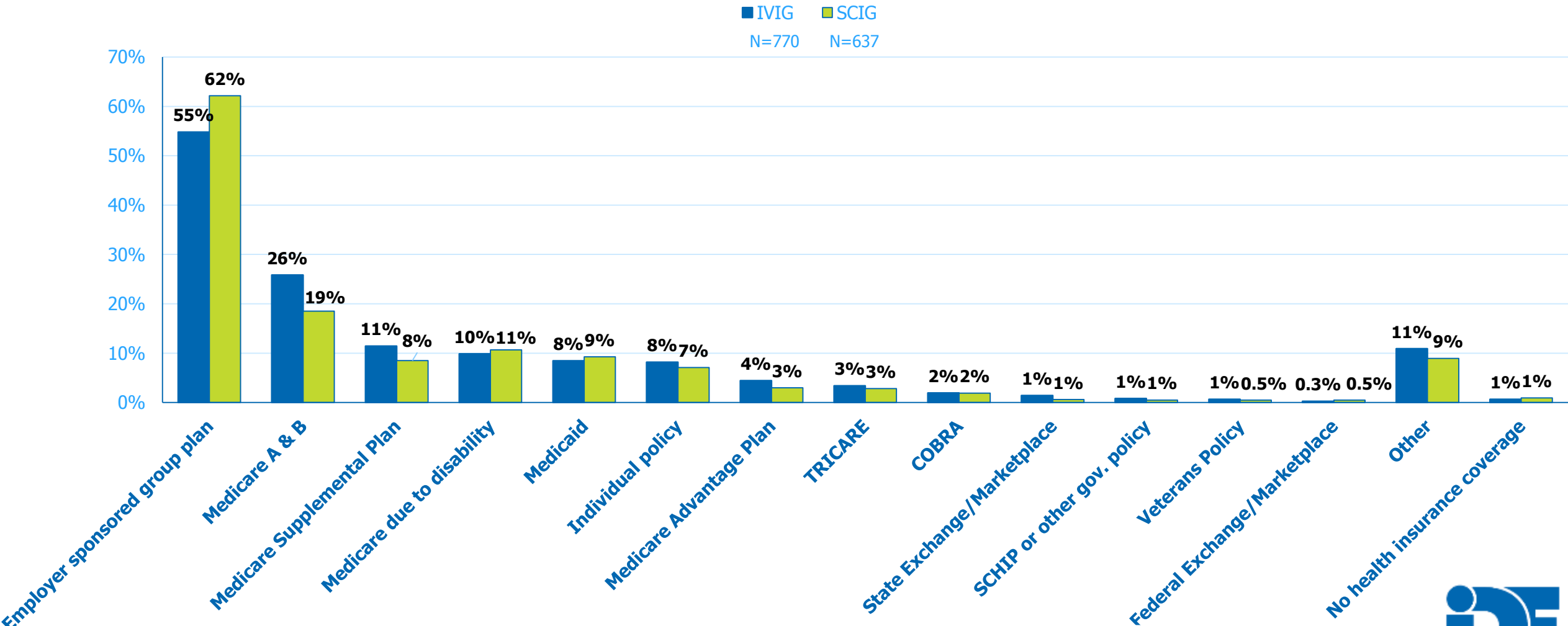
■ Less than 1 month ■ 1 to 6 months ■ Longer than 6 months ■ Did not take any antibiotics



Q62. In the past 12 months, how long has the patient taken antibiotics for an active infection? N=1,365
Base: Patients who currently use IVIG or SCIG



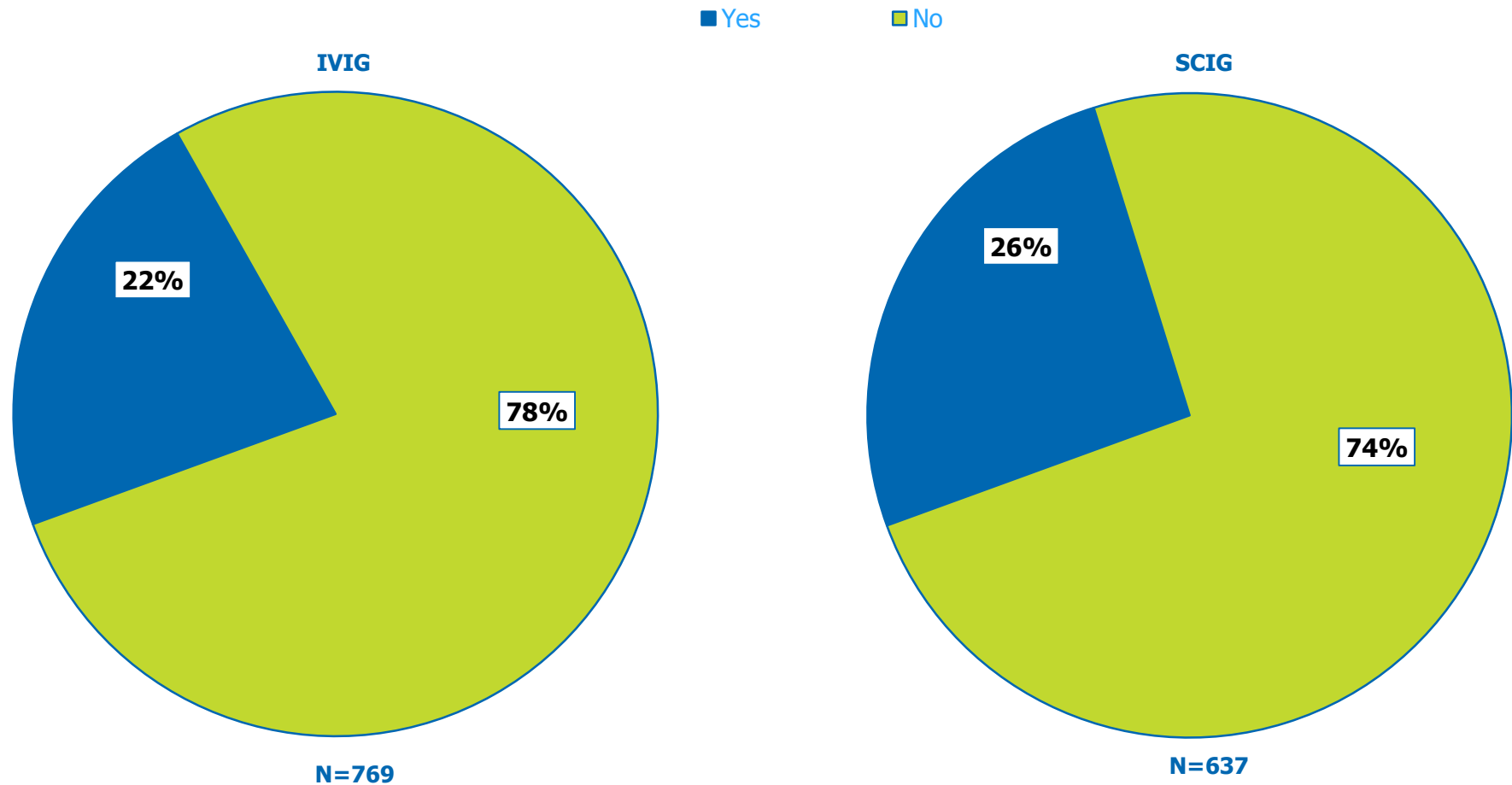
Current Health Insurance IVIG vs. SCIG



Q63. What kind of health insurance does the PATIENT currently have? SELECT ALL THAT APPLY
Base: Patients who currently use IVIG or SCIG



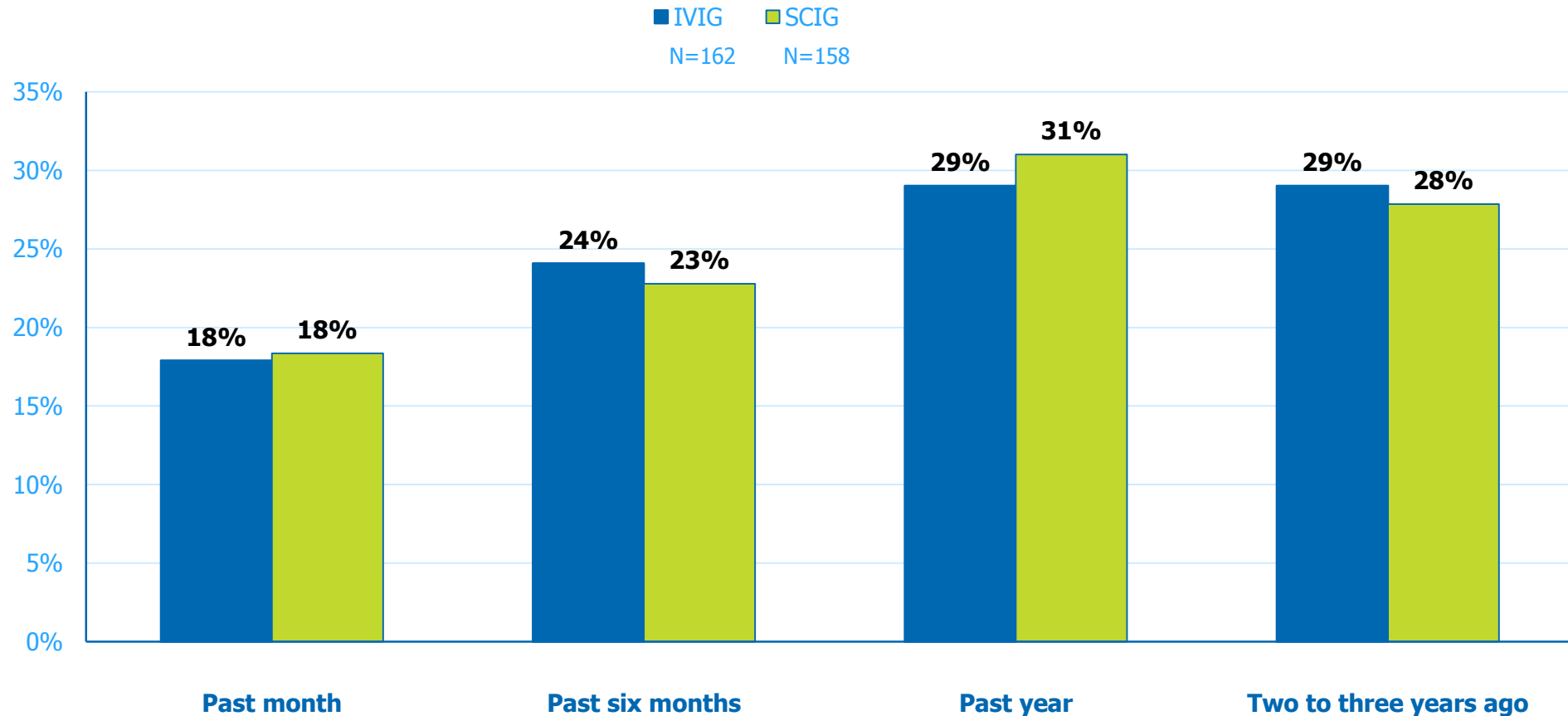
Problem Getting Regular Infusion



Q64. In the past three years, due to health insurance, has the patient ever had a problem in getting his/her regular infusion?
Base: Patients who currently use IVIG or SCIG



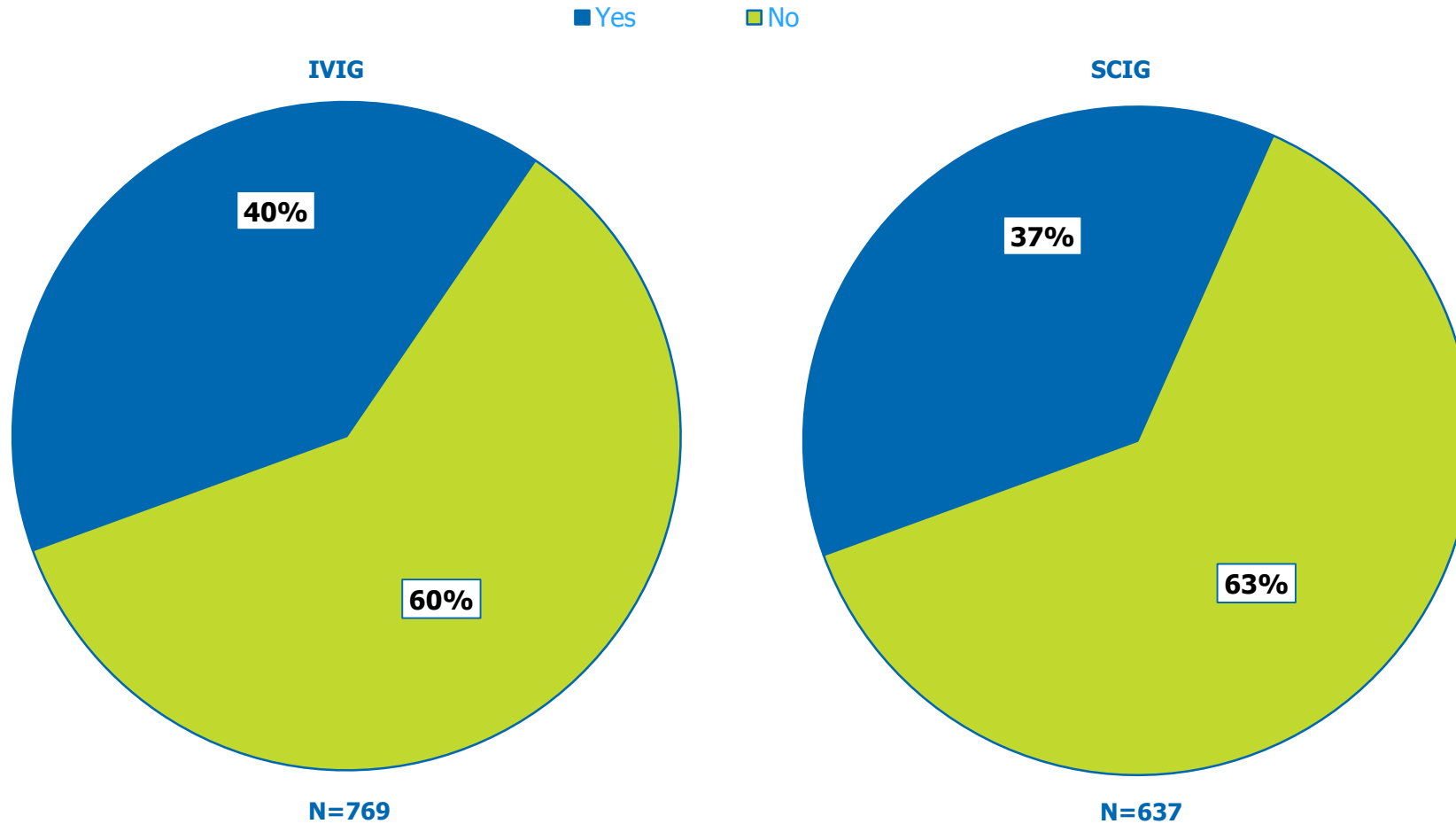
Last Time Patient Had A Problem Getting Their Regular Infusion



Q65. When was the most recent time the patient had a problem getting his/her regular infusion due to health insurance?
Base: Patients who currently use IVIG or SCIG

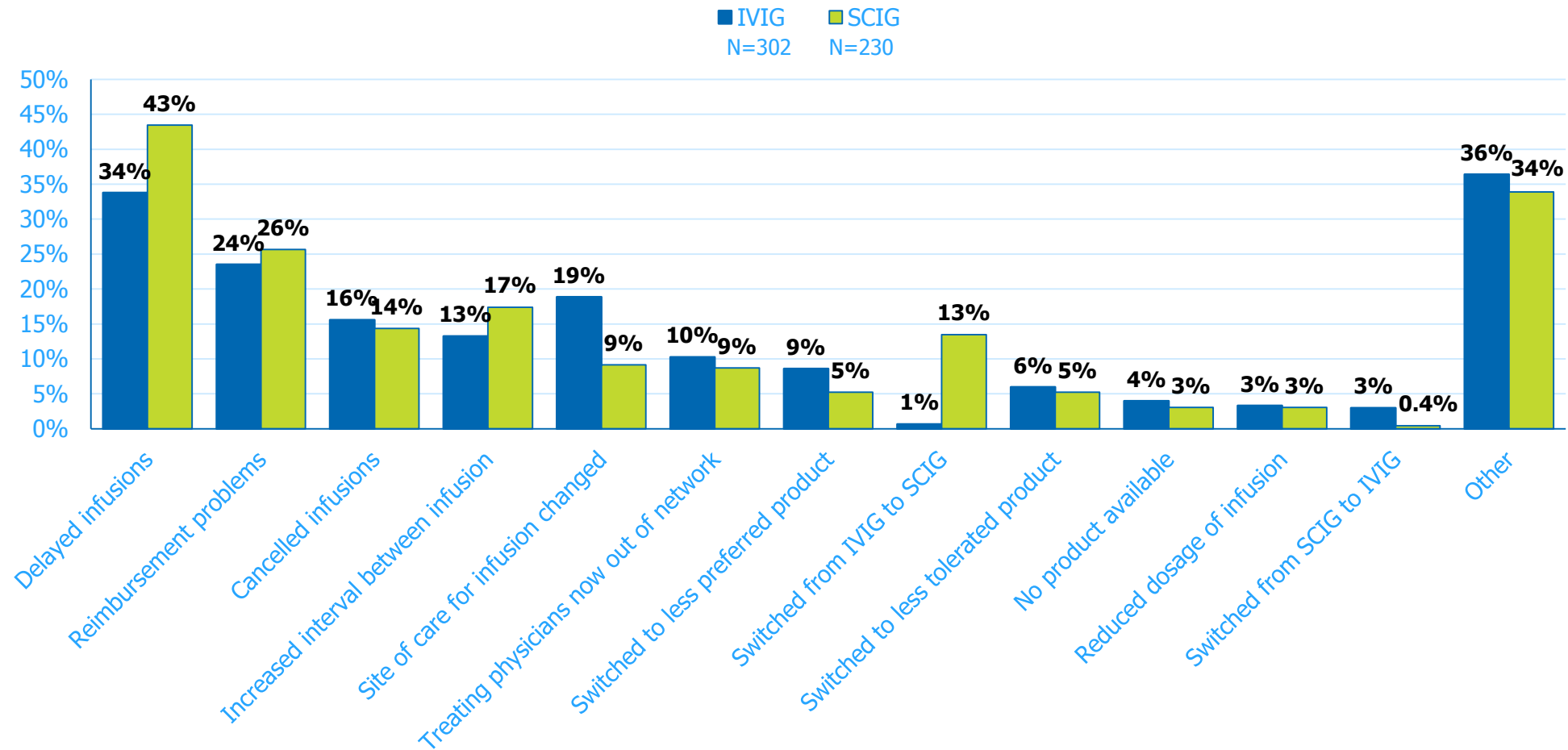


Problems Due to Health Insurance



Q66. In the past 12 months, which of the following problems, if any, has the patient experienced due to health insurance?
Base: Patients who currently use IVIG or SCIG

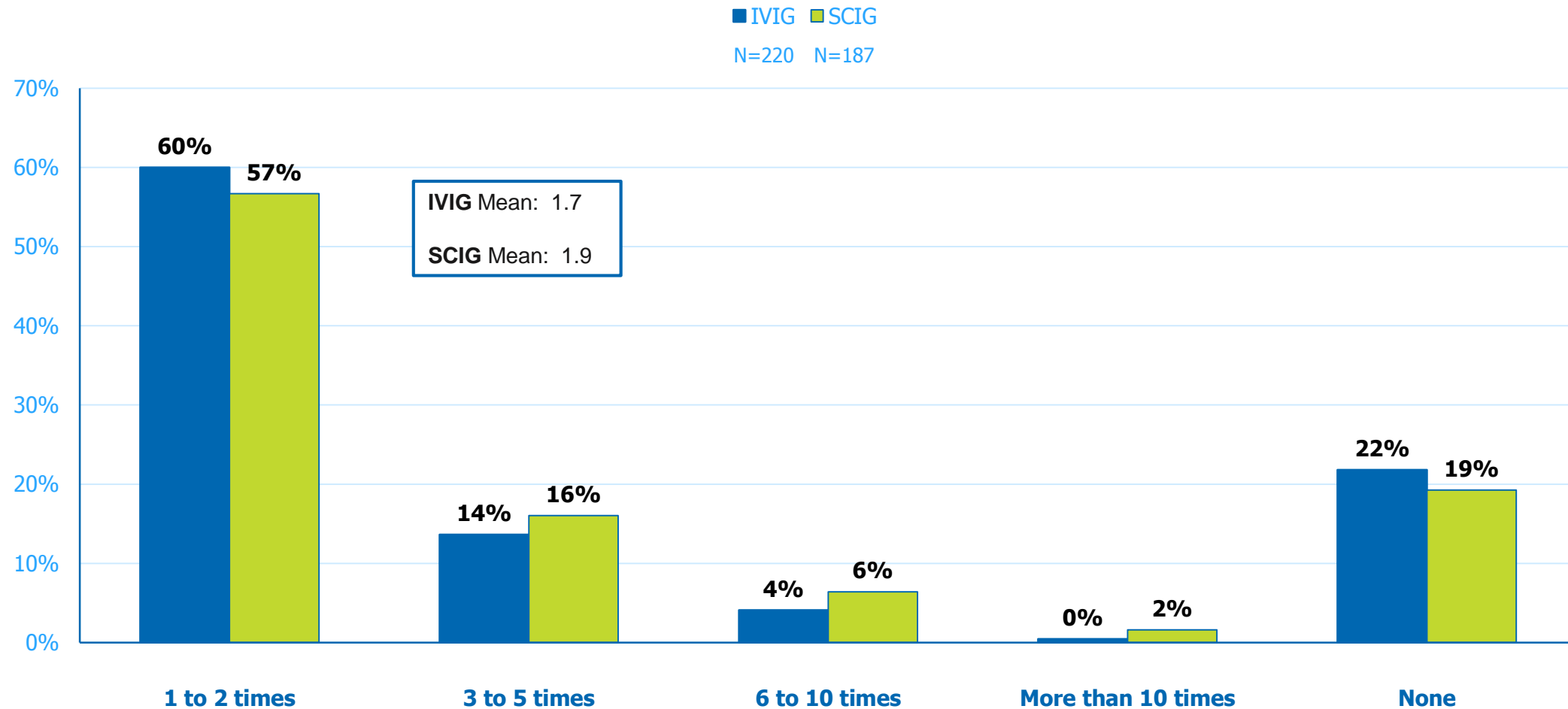
Problems Due to Health Insurance



Q66. In the past 12 months, which of the following problems, if any, has the patient experienced due to health insurance? SELECT ALL THAT APPLY

Base: Patients who currently use IVIG or SCIG who experienced problems due to health insurance

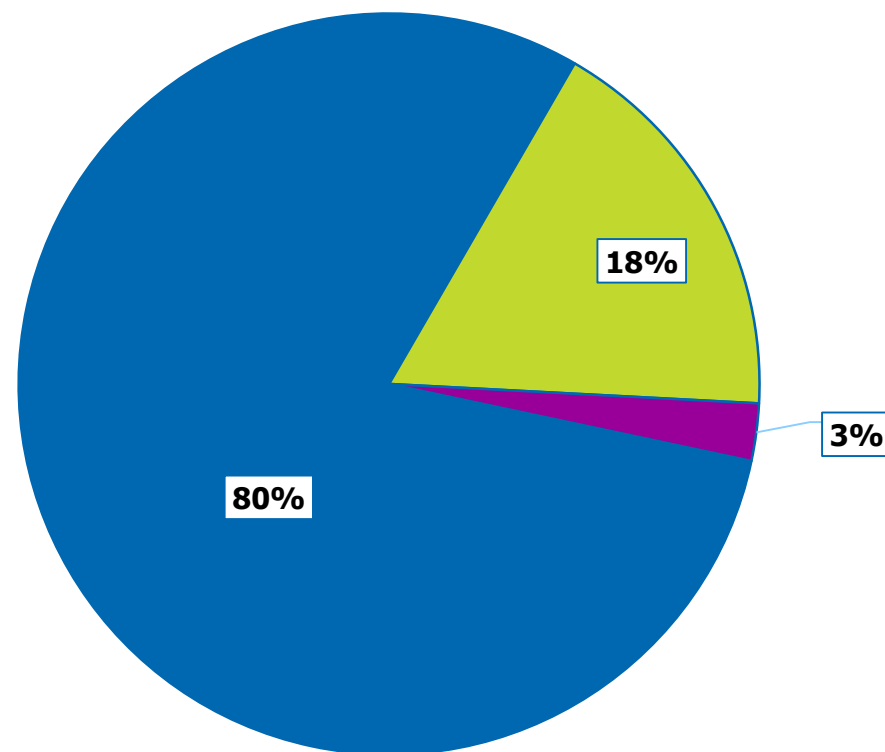
Number of Times Patient Had a Problem Getting Regular Infusion



Q67. How many times in the past 12 months has the patient experienced a problem getting his/her regular infusion?
Base: Patients who currently use IVIG or SCIG

Patient or Parent/Caregiver

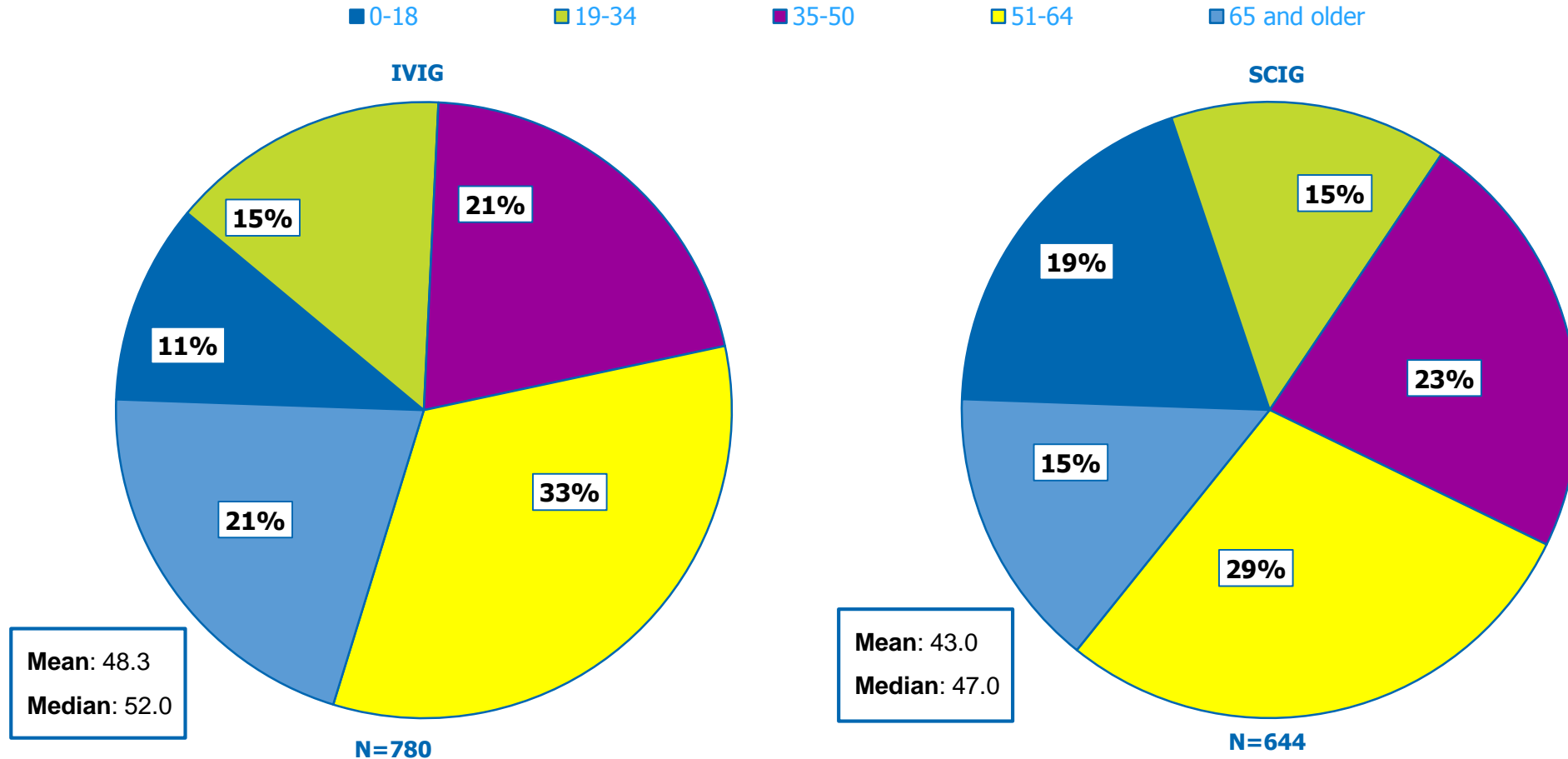
■ PI Patient ■ Parent/caregiver ■ Both



Q1. Are you a patient with a primary immunodeficiency disease (PI) or parent/caregiver of a child in the household with PI? N=1,425
Base: Respondents that are currently receiving IVIG or SCIG



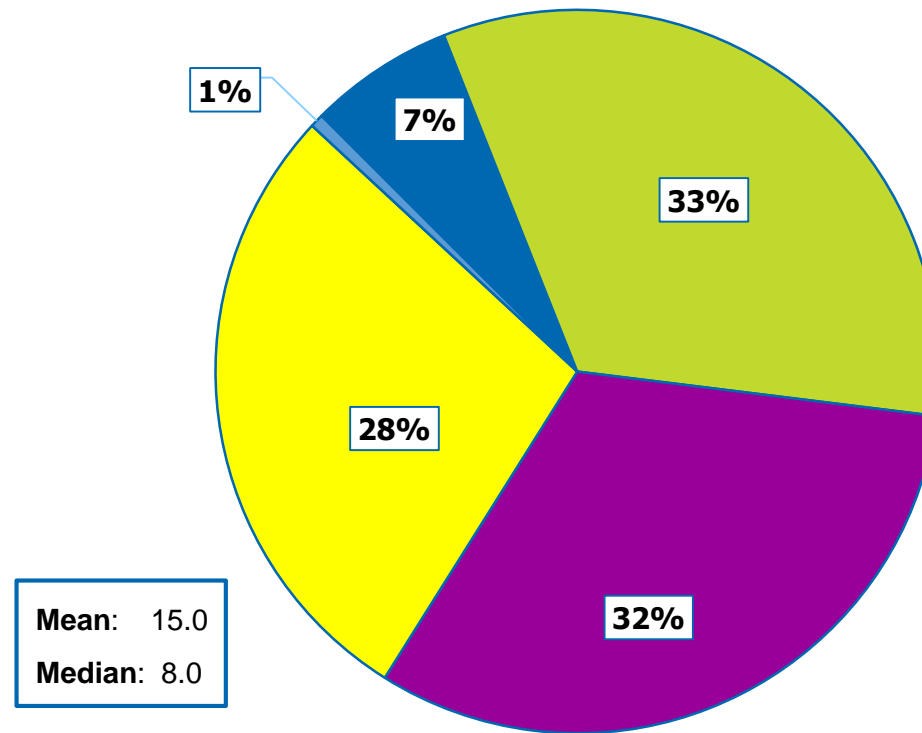
Age of Patient IVIG vs. SCIG



Q2. What is the date of birth of the (adult patient/oldest child) in the household with a primary immunodeficiency disease?
Base: Respondents that are currently receiving IVIG or SCIG

Years from Onset of Symptoms to Diagnosis

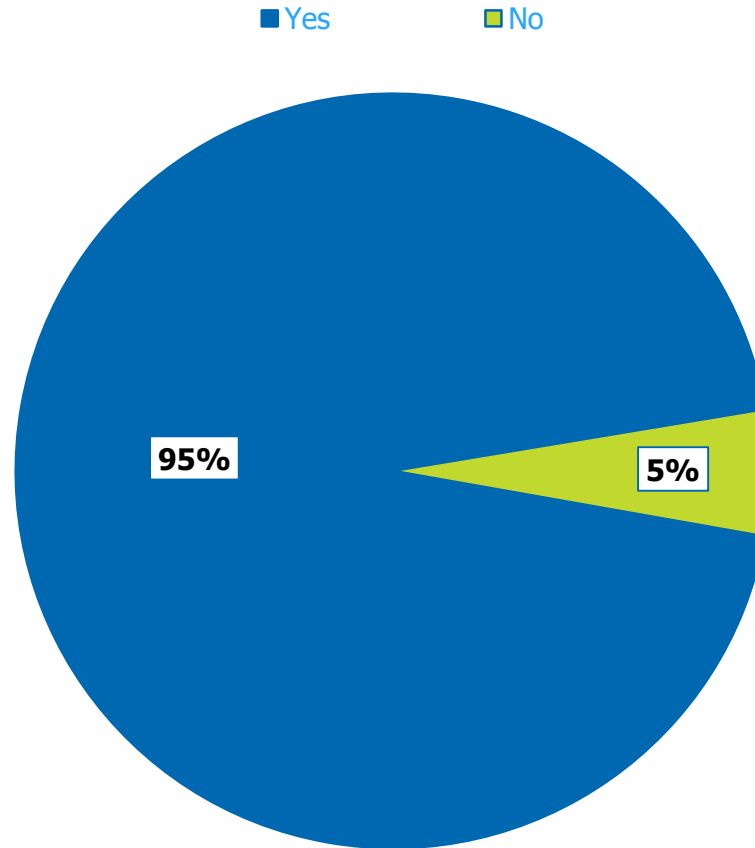
■ At birth ■ 1 to 5 years ■ 6 to 20 years ■ More than 20 years ■ Symptoms presented after diagnosis



Q4. At what age (in years) was that person first diagnosed with a primary immunodeficiency disease?
Q6B. At what age (in years) did these repeated, serious, or unusual infections begin? N=1,251
Base: Patients that are currently receiving IVIG or SCIG



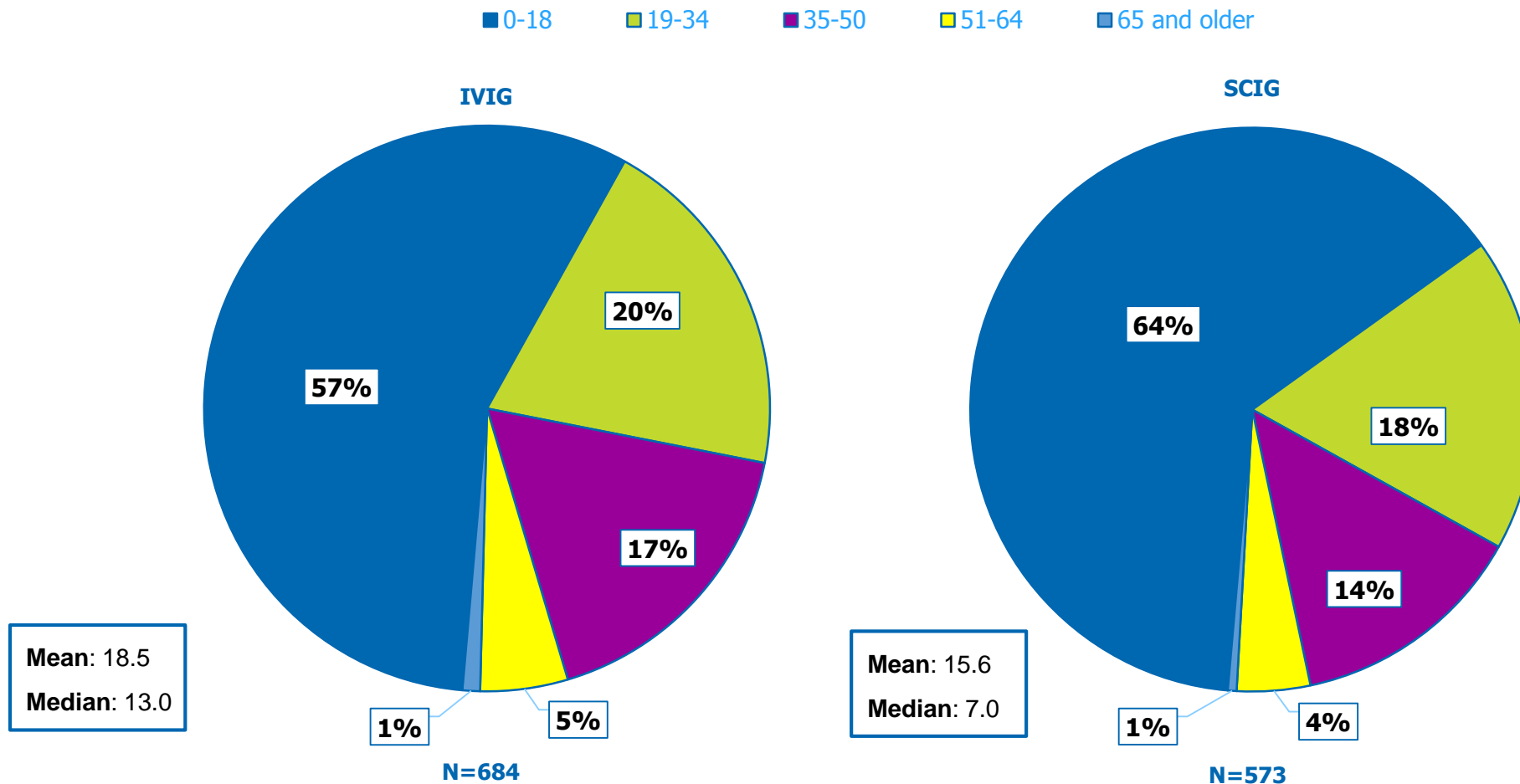
Prior to Diagnosis: Repeated, Unusual or Serious Infections



Q6a. Did the patient experience repeated, serious, or unusual infections prior to initial diagnosis as immune deficient? N=1,420
Base: Patients that are currently receiving IVIG or SCIG

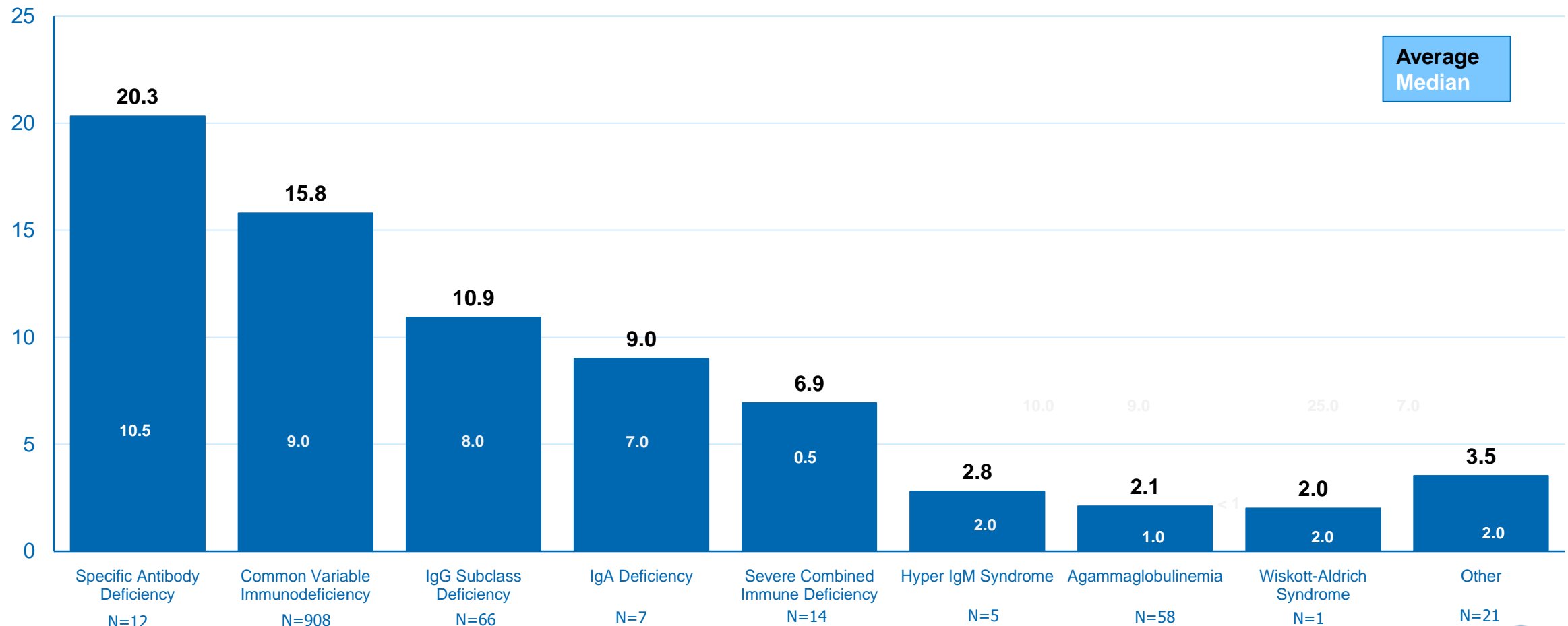


Prior to Diagnosis: Age of Onset of Repeated, Unusual or Serious Infections IVIG vs. SCIG



Q6B. At what age (in years) did these repeated, serious, or unusual infections begin?
Base: All patients who are currently taking IVIG or SCIG who experienced repeated, serious, or unusual infections prior to initial diagnosis

Years from Onset of Symptoms to Diagnosis by PI Diagnosis



Q4. At what age (in years) was that person first diagnosed with a primary immunodeficiency disease?
 Q5. What is the specific diagnosis of that person's immunodeficiency disease?
 Q6B. At what age (in years) did these repeated, serious, or unusual infections begin?
 Base: Patients that are currently receiving IVIG or SCIG with only 1 PI diagnosis



Take Aways

Type of Ig Therapy

- 55% of patients currently use IVIG and 45% of patients currently use SCIG.
- Current SCIG users are younger (mean age: 43 years old) than current IVIG users (mean age: 48 years old).
- Patients who currently use IVIG overwhelming (83%) report IVIG as the only Ig therapy they have ever used.
- Conversely, a little more than a quarter of current SCIG users (27%) report only using SCIG for their Ig therapy.
- SCIG users were more likely to have used IVIG and SCIG (66%). Only 12% of current IVIG users used both IVIG and SCIG.



Take Aways

No Longer Using Ig Therapy

- Patients that no longer use any form of Ig therapy were more likely to report their physician terminated their Ig therapy because it was no longer deemed medically necessary.
- This occurred more often with patients who used SCIG only versus patients that used IVIG only or both IVIG and SCIG.



Take Aways

Other Chronic Conditions

- Asthma (55%), Arthritis (50%), Autoimmune Condition (37%), Digestive Disease (34%), and Malabsorption/Diarrhea (29%) were among the top five chronic conditions reported by current Ig users in the past 12 months.
- Chronic conditions such as Arthritis, Autoimmune Condition, Neurological Disease and Cancer all increased - by more than 2 percentage points - post diagnosis for current Ig therapy users while all other chronic conditions decreased.



Take Aways Infections

- The number of current Ig users reporting infections decreased post diagnosis.
 - For example:
 - Prior to Diagnosis
 - 67% of IVIG users had Bronchitis
 - 71% of SCIG users had Bronchitis
 - 55% of IVIG users had Pneumonia
 - 53% of SCIG users had Pneumonia
 - In the Past 12 months
 - 36% of IVIG users had Bronchitis
 - 38% of SCIG users had Bronchitis
 - 15% of IVIG users had Pneumonia
 - 11% of SCIG users had Pneumonia
- In the past 12 months, current IVIG users reported more occurrences of Sinusitis, Ear Infections, Candia and Eye Infections than SCIG users. Current SCIG users reported more occurrences of Diarrhea and Skin Infections than IVIG users.



Take Aways Side Effects

- The top five side effects for current IVIG users were fatigue, headache, chills, weakness and nausea.
- Most common side effects for current SCIG users were redness at infusion site, swelling at infusion site, fatigue, headache, and blood in tubing.
- IVIG users were more likely to report not experiencing any side effects (13%) than SCIG users (10%).
- Ig therapy users reported serious side effects such as aseptic meningitis, blurred vision and blood clots.



Take Aways

Perceived Effectiveness and Satisfaction

- 57% of current IVIG users reported their Ig therapy completely controls or well controls their PI vs. 61% of current SCIG users.
- 44% of current IVIG users always experience a wear off effect vs. 27% of current SCIG users
 - 57% IVIG users report the wear effect lasts for 1 to 3 weeks vs. 90% of SCIG users who report less than 1 week.
- Both IVIG (77%) and SCIG (77%) are equally satisfied with the Ig product they currently use.



Take Aways

Prophylactic Antibiotic Therapy

- 54% of IVIG users have taken antibiotics along with their Ig therapy to help prevent infections vs. 48% of SCIG users.
- When compared, IVIG users report better control of PI with Ig therapy alone (65% completely or well controlled) than IVIG and antibiotics (50%). Similar results were reported for SCIG users, 68% SCIG alone vs. 53% SCIG and antibiotics.

