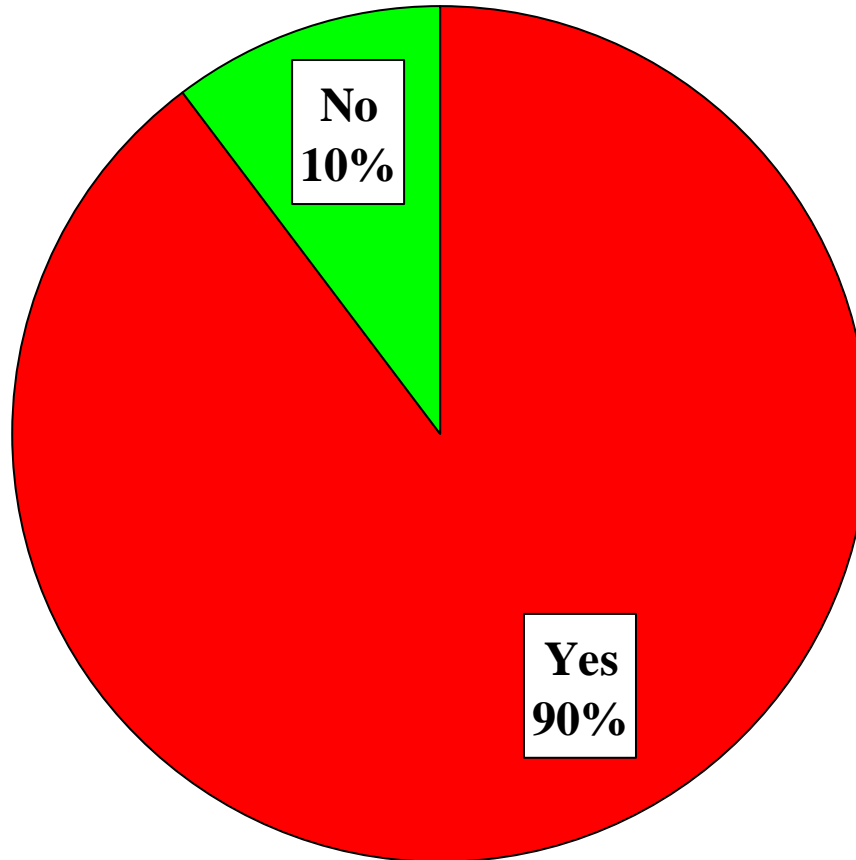


IDF Survey of Patients using IVIG: 1997



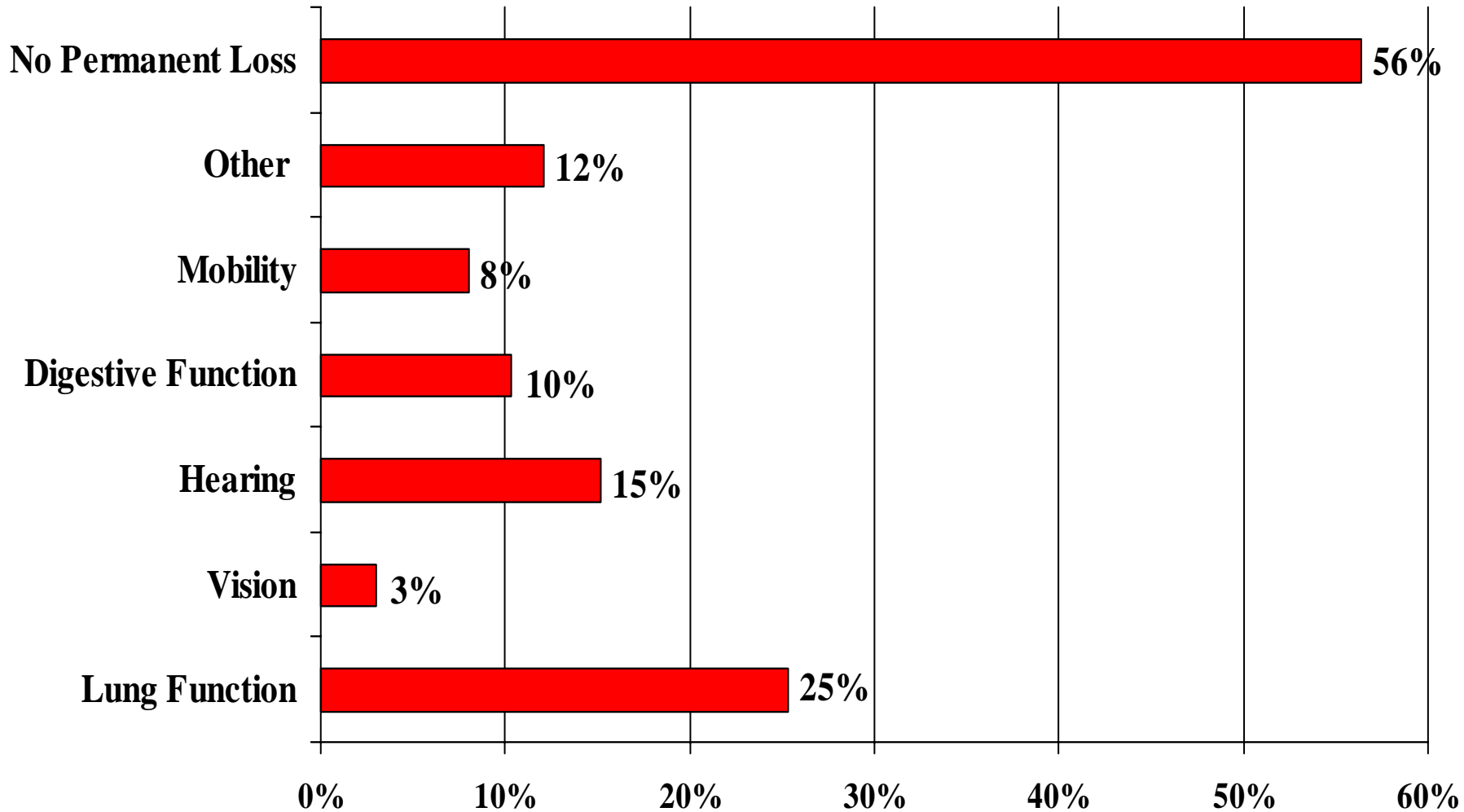
Conducted among Patients from the
First National Patient Survey (1996)
who had been treated with IVIG

Repeated or Unusual Infections Prior to Diagnosis



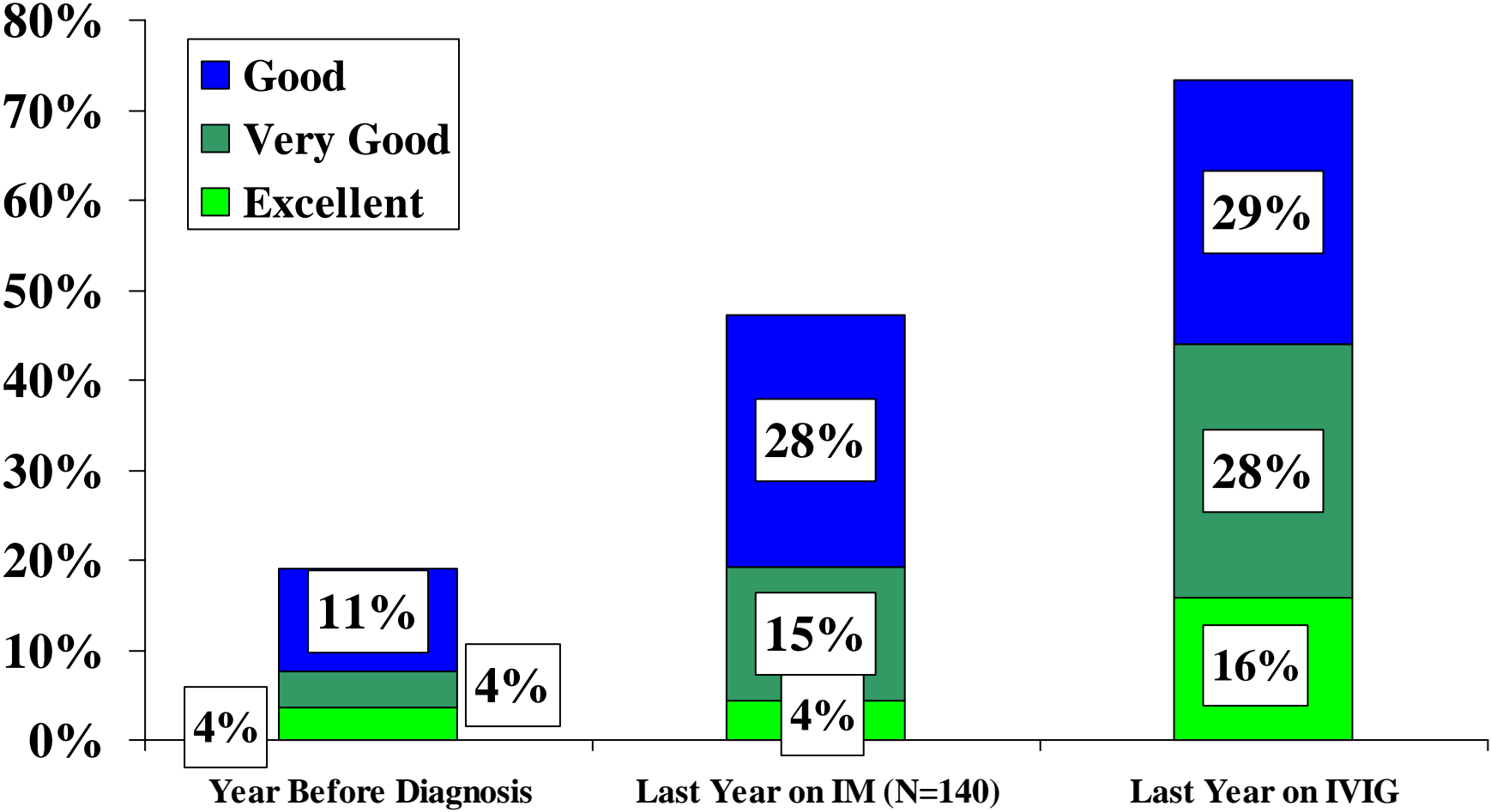
Q3. Did the patient exhibit repeated or unusual infections prior to diagnosis as immune deficient?
N=908

Permanent Functional Impairment Prior to Diagnosis



Q5. By the time the patient was initially diagnosed as immune deficient, had he/she suffered any permanent loss of

Health Status: Before and After Treatment



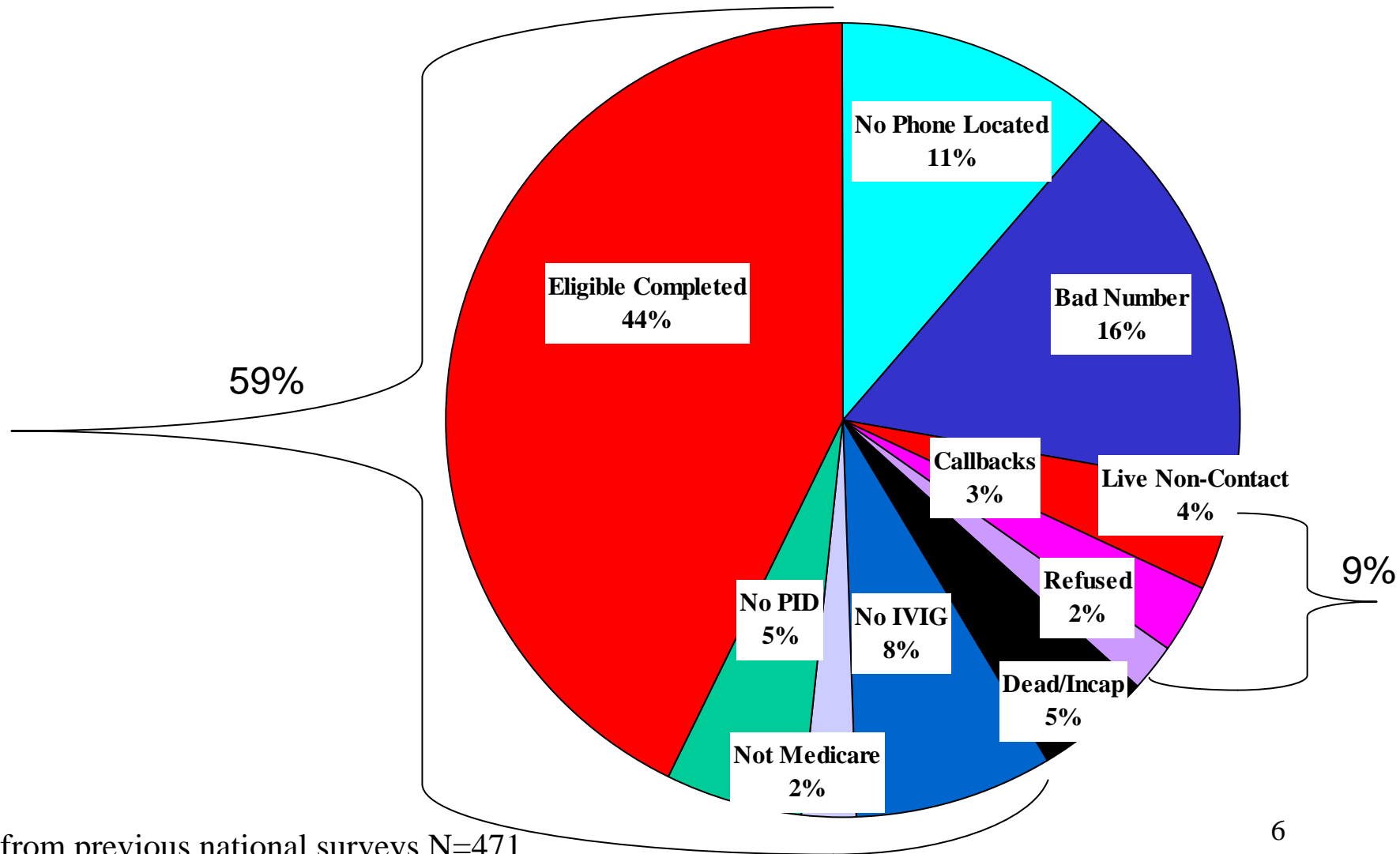
Q6/Q60. Overall, how would you describe his or her health (in the year prior to diagnosis/during the last year (on IM/IVIG)?

*Survey of Intravenous Immunoglobulin
Availability and Access among Medicare Patients
with Primary Immune Deficiency Diseases:
May-July 2005*

Immune Deficiency Foundation

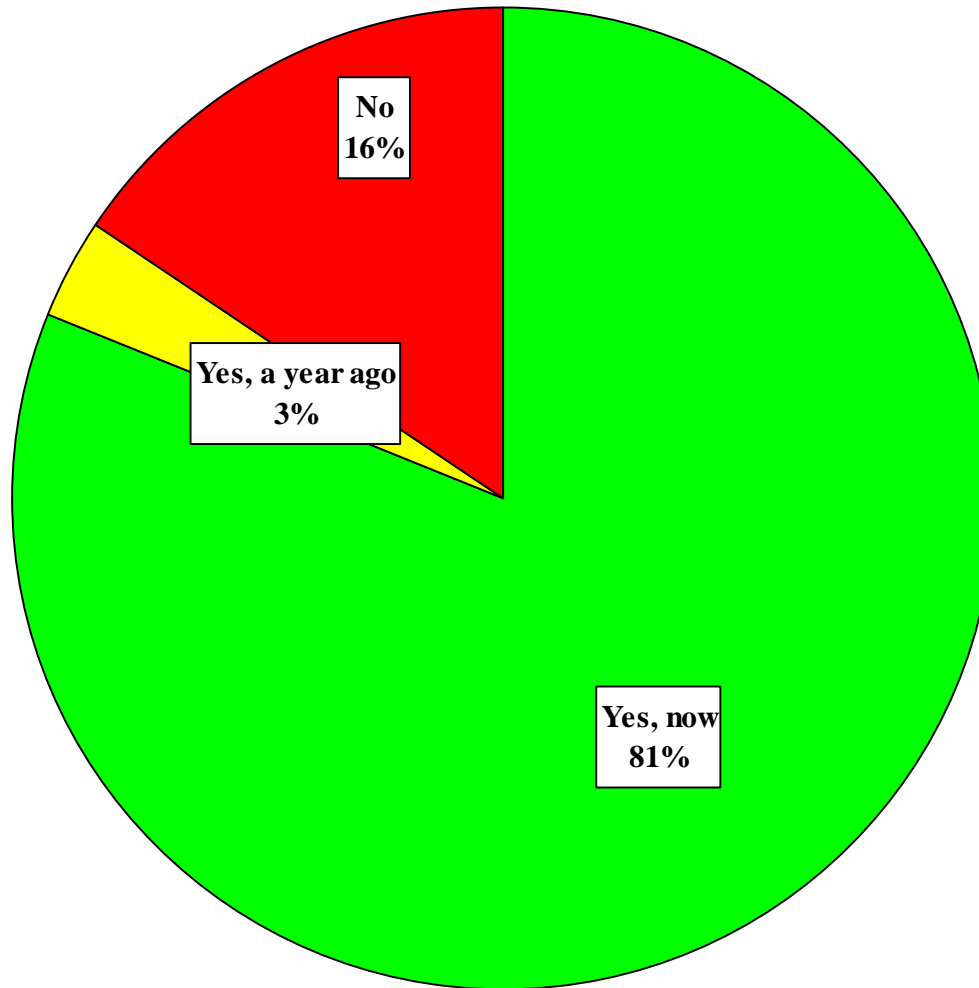
September 19, 2005

Sample Disposition for Medicare Patient Survey: 2005



Cases from previous national surveys N=471

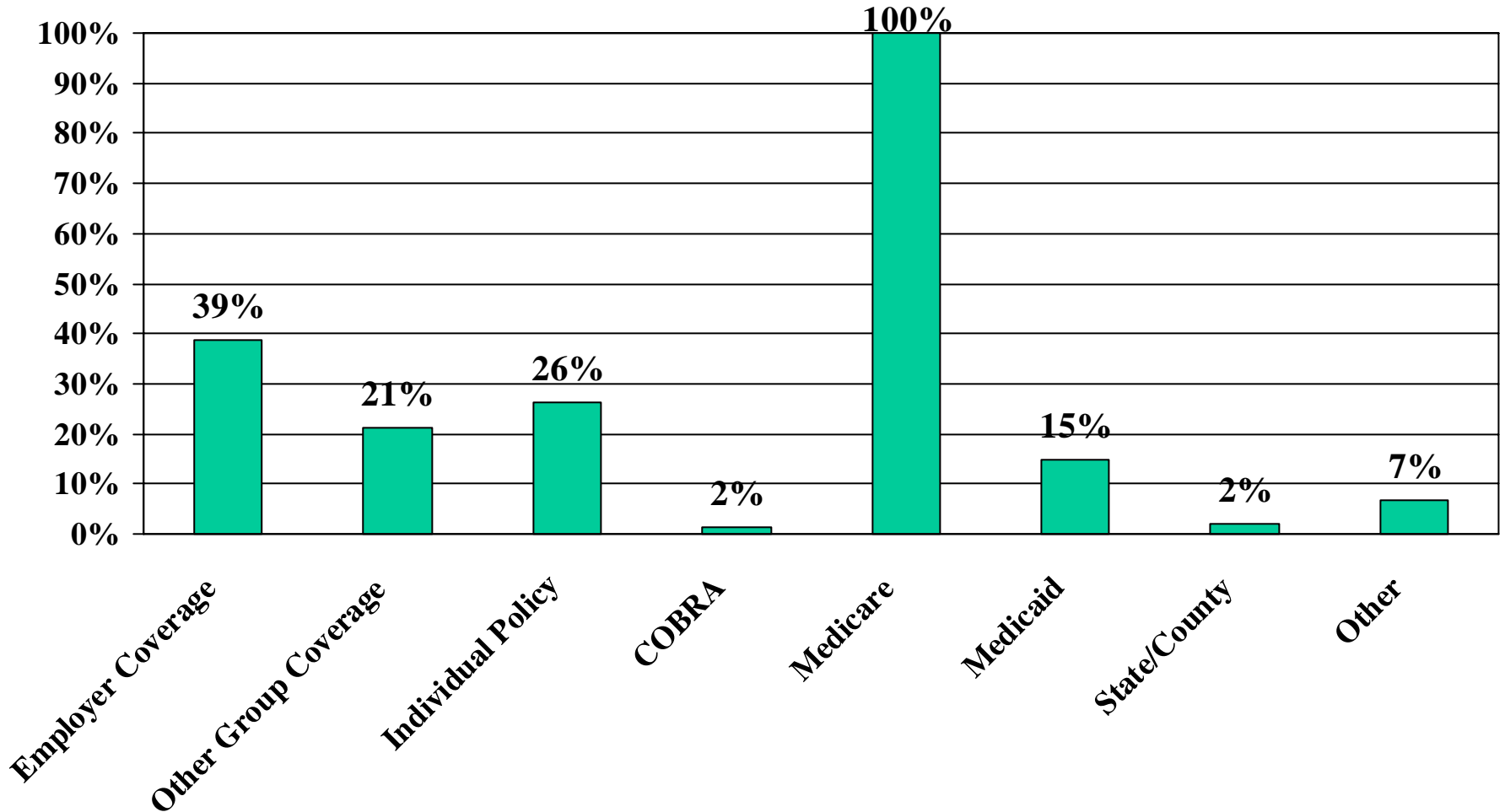
IVIG Use: Medicare Patients



Q3a. Is he/she currently being treated with IVIG for this condition?

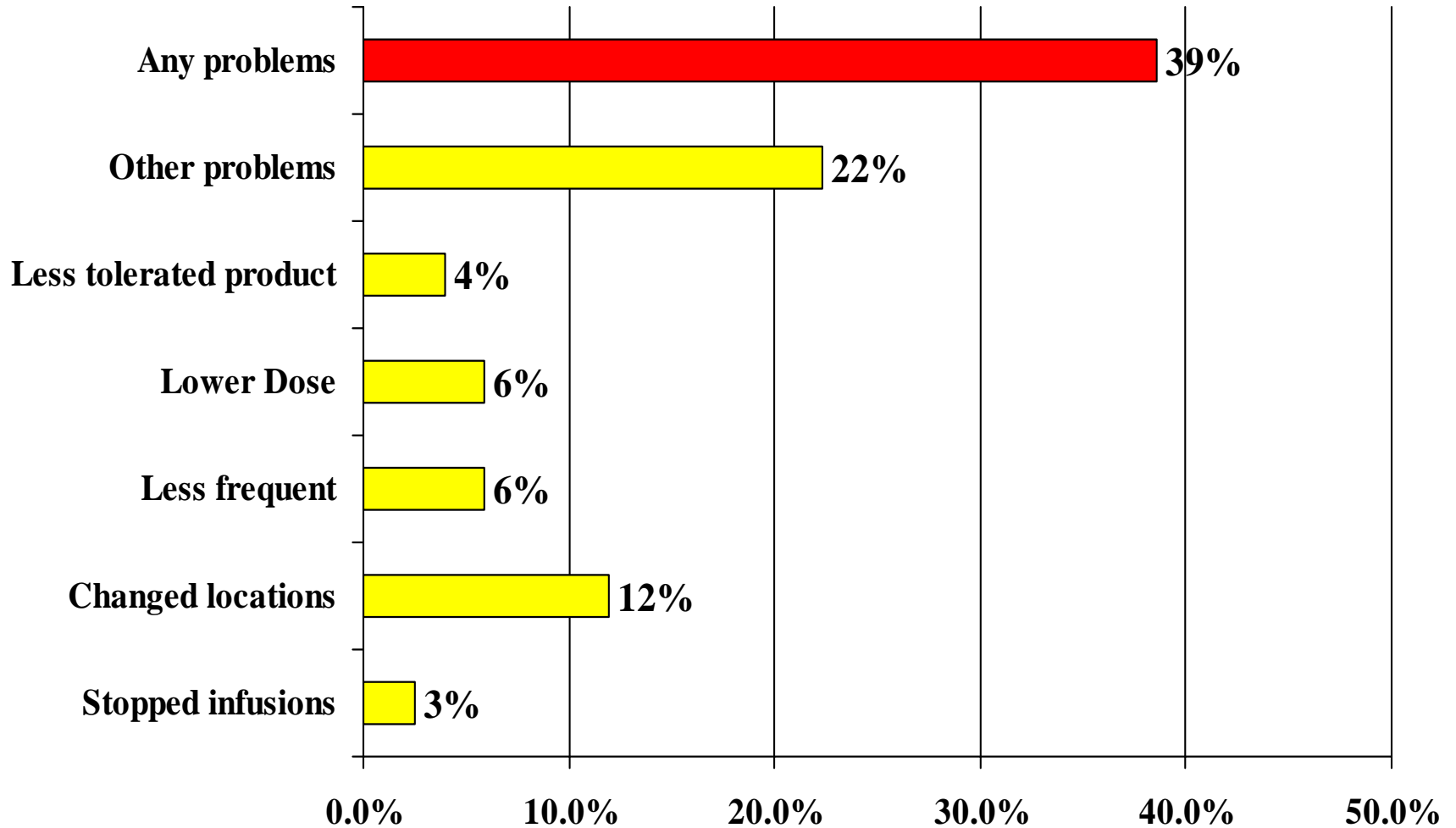
Q3b. Was he/she being treated with IVIG a year ago? N=239

Source of Current Health Insurance

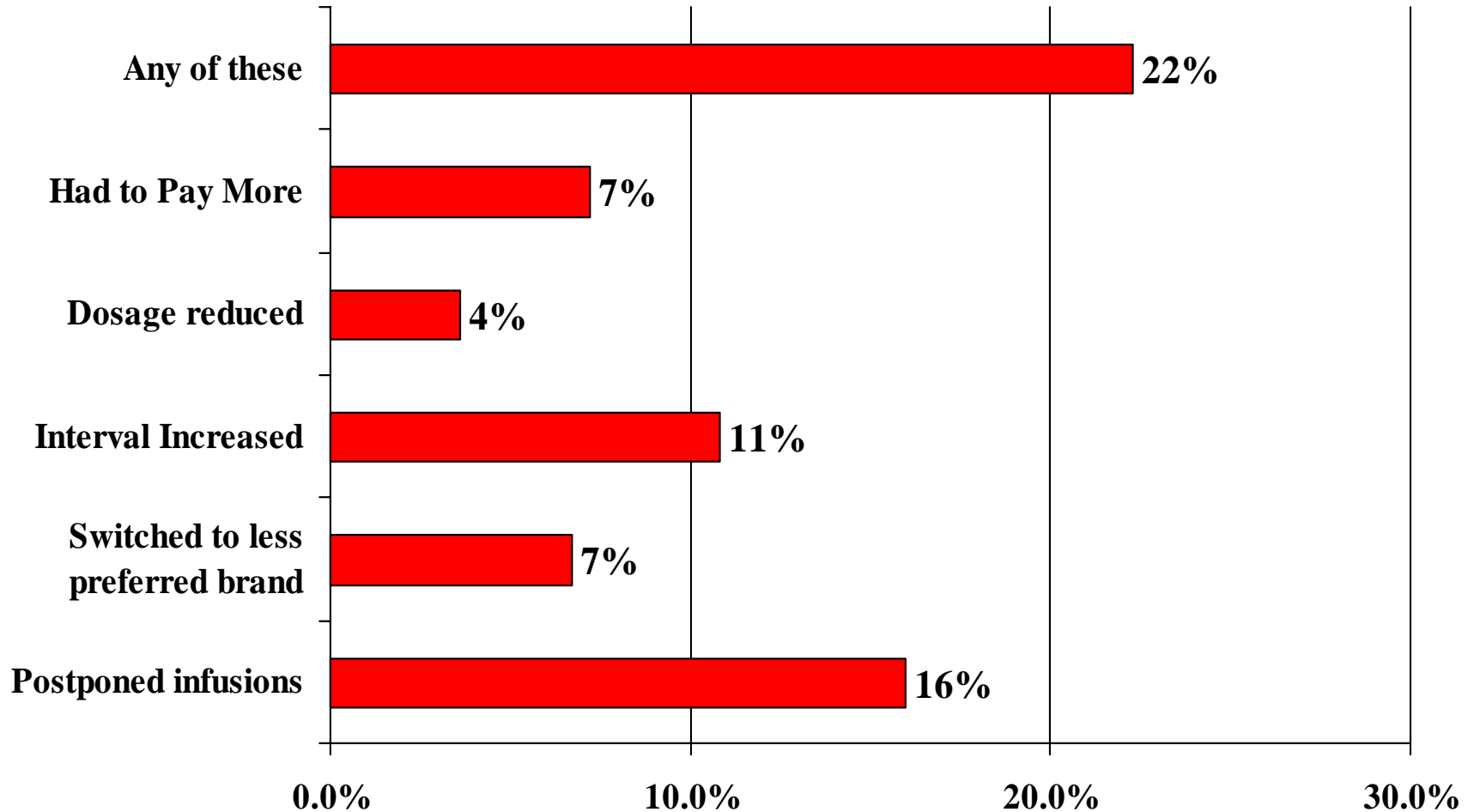


Q2. What is the current source(s) of the patient's health care coverage?
(Base: Have Medicare and Use IVIG a Year Ago N=202)

IVIG Problems For Medicare Patients: Summary

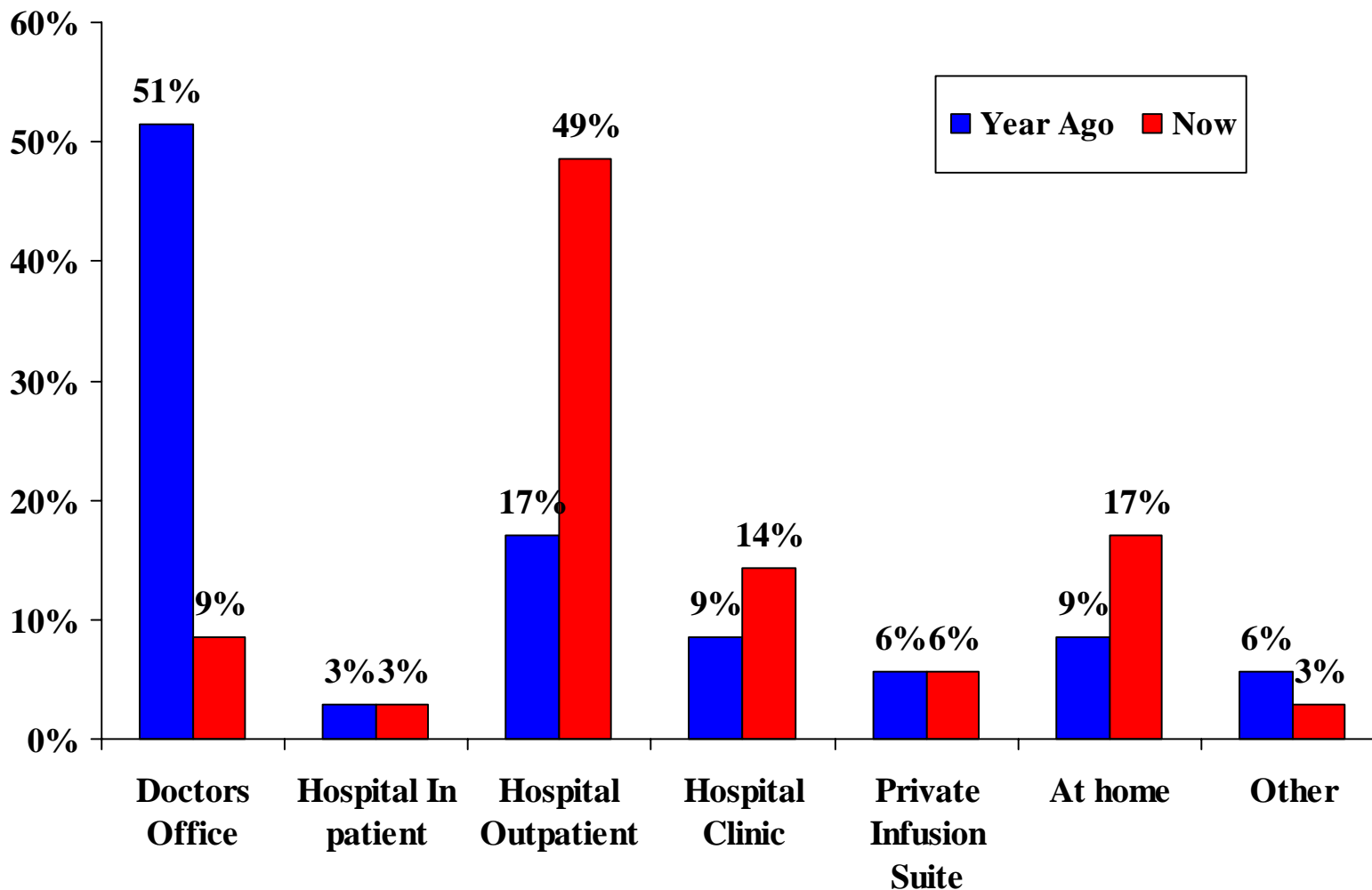


Impact of IVIG Problems in Past 12 months



Q14B. As a result of these problems during the past 12 months have you? Current user N=194

Change in Site of Infusions



Q4a. A year ago, where did the patient usually receive his/her infusions? Q4b. Does he/she still get his/her infusions at the same location? Q4c. Where does he/she get his/her infusions now?

Base: Has changed infusion site N=35

Why Changed Site of Infusion

- Because Medicare reimbursement rates were lowered
- Because Medicare changed the funding and policies changed.
- Because Medicare wouldn't pay the private doctor anymore.
- Dr X asked this company to accept Medicare & they don't take everybody. because Medicare cut the doctors payment.
- Due to Medicare change in what they are paying the doctor per gram in the infusions
- The change in the Medicare payments. They cut the amount that they would pay to doctors and as a result the doctor's could not buy the gamma at a price that they could make any profit
- The doctors were no longer being reimbursed for gamma globulin by Medicare. They reduced the amount so low that it would have cost the doctors more, they would have lost money on it.
- **The explanation I got from my doctor was that Medicare had started not reimbursing enough to cover the doctors office cost. That sort of floored me because Medicare and my insurance is now paying about \$648 more than they were paying the doctors office.**
- The reimbursement rate for the doctor was lowered by Medicare
- Because Medicare would not cover it at physicians office
- Because Dr. X can't afford to pay for all these pts treatments; he couldn't get reimbursed

Why Less Frequent Infusions

- Medicare is dictating the frequency to the doctors and taking the care out of the doctors hands for the patient.
- The hospital doesn't have enough IGG so they postponed the frequency because of the shortage
- The hospital said due to shortage in the gamma, in buying it, so they were going to put me off for 4 weeks instead of 2 weeks until i notified the hospital that i was in contact with IDF and my congressman. Then they switched me back to every 3 weeks.
- They decided to try me at every 2 mo & after 3wks they &I figured out that wasn't going to wk. (It was related to the Medicare reimbursement & I offered to make up the difference in\$\$, but they never accepted any money)
- They didn't give me an answer as to why, my bill was so high because each month that one line takes thousands of dollars, it varies, there for a while it was 10 thousand and sometimes 11 thousand per month.
- **Because the hospital was having problems with Medicare paying for this and they would not treat me unless my level was below 600 and normal is 1000...My doctors decided to extend it to 8 weeks hoping levels would stay below 600 but having sinus infection**
- Because of Medicare's new ruling, the hospital just said that because of Medicare's new ruling they will give it to me every 3-4 weeks

Why Changed to Less Tolerated Product

▪Based on availability, Polygam simply happens to be the drug that this particular hospital had. When I'm here in Ohio I have no idea what product they'll give me, based on availability.

▪**Because I had to change locations because of the Medicare pricing change. .Also didn't react well to last medication at doctor's office that was xx, which was changed due to pricing.**

▪Because it meant that the doctors got reimbursed more.

▪Because that's the only product that the hospital had, that's all they had to offer.

▪Because the doctor was very arrogant and didn't listen and i was getting a product without that

▪Because the hospital buys it in bulk.

▪Because they didn't have the other one.

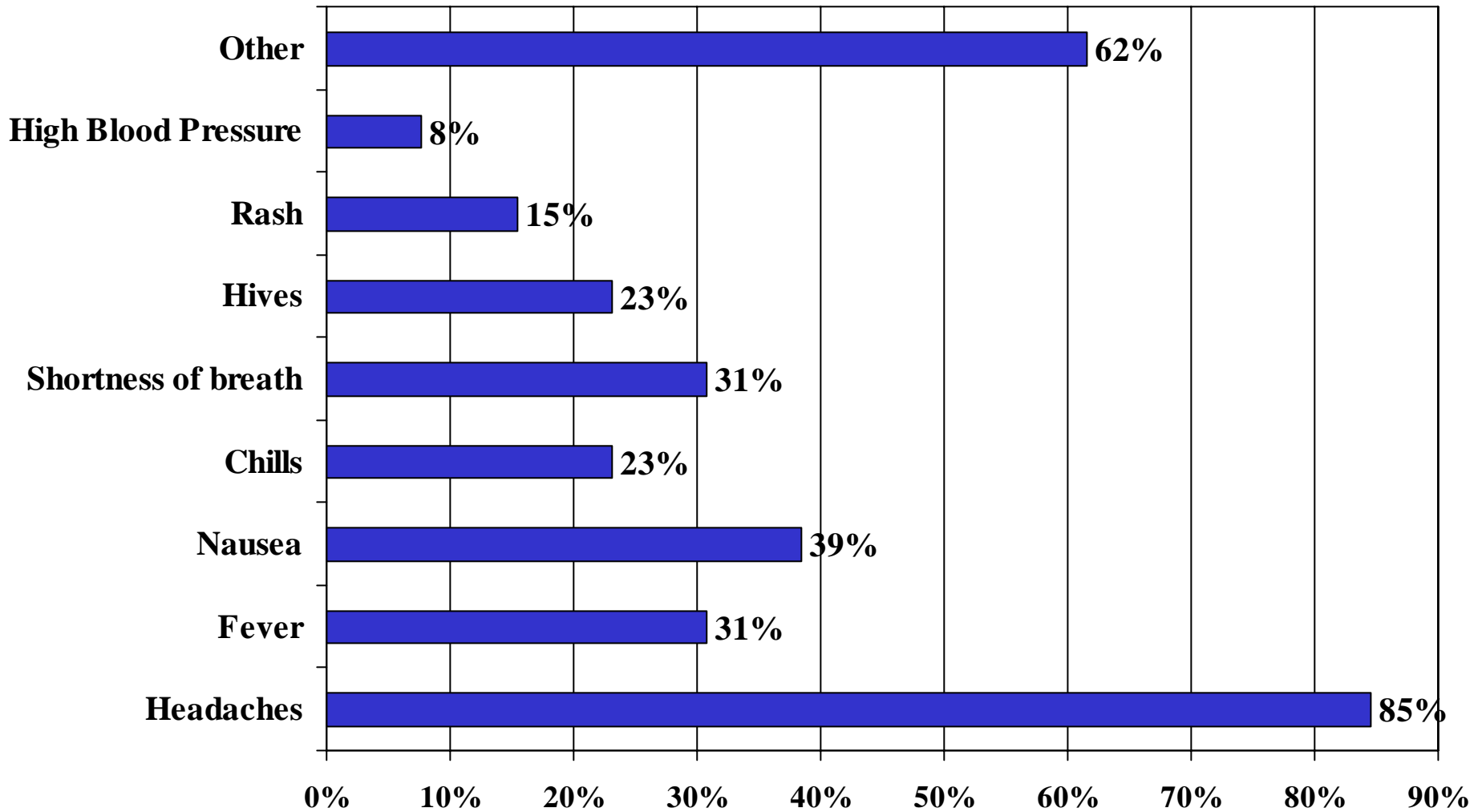
▪Because they quit making IVEEGam and I was taking it

▪Because when I changed hospitals the new hospital stocks a different brand.

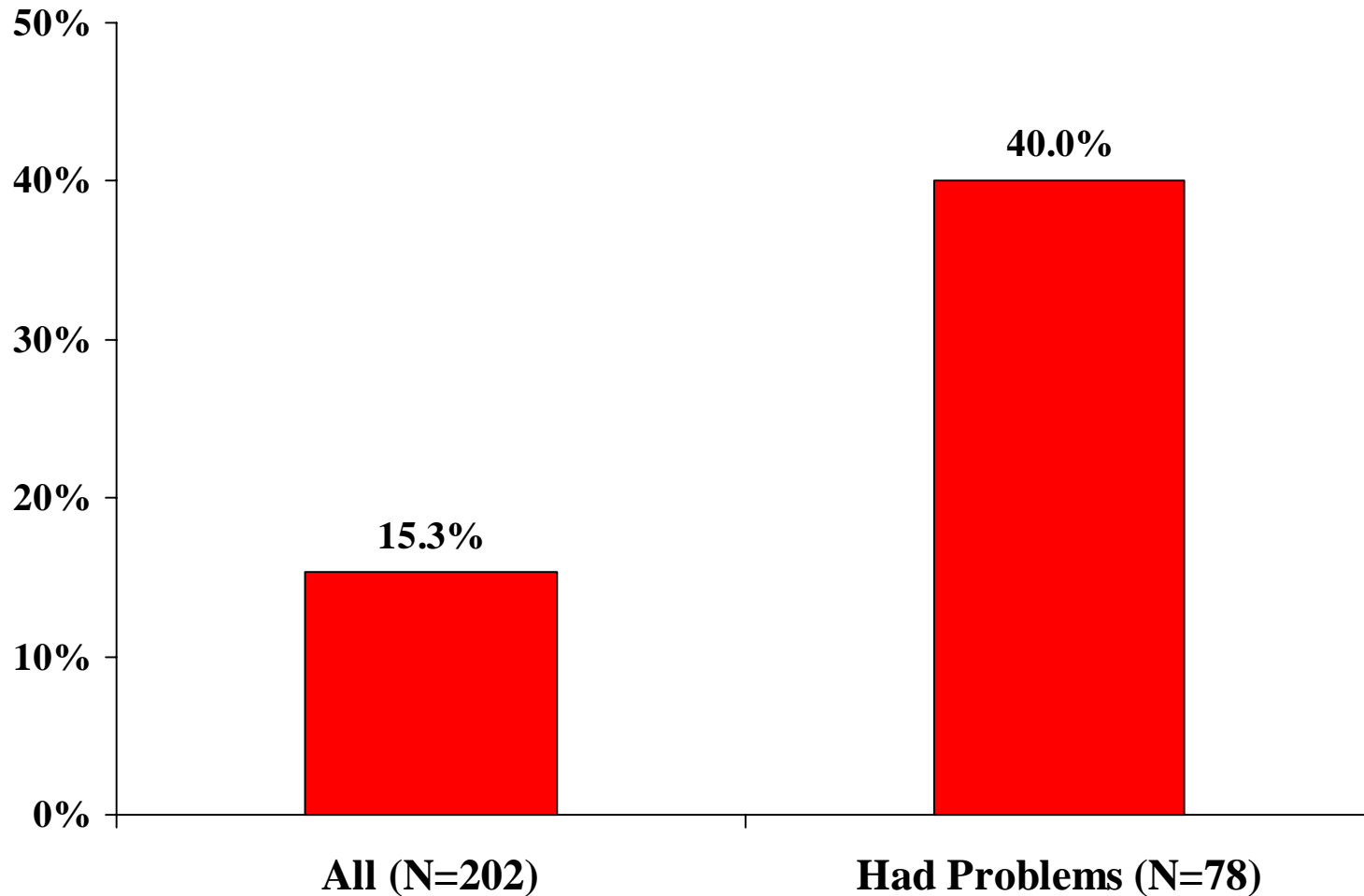
▪I believe that there were issues of supply and the ability to purchase it at a rate covered by reimbursement guidelines by Medicare

▪The hospital gives you what they have available in their pharmacy

Side Effects from New Product



Negative Health Effects as a Result of Problems Getting IVIG

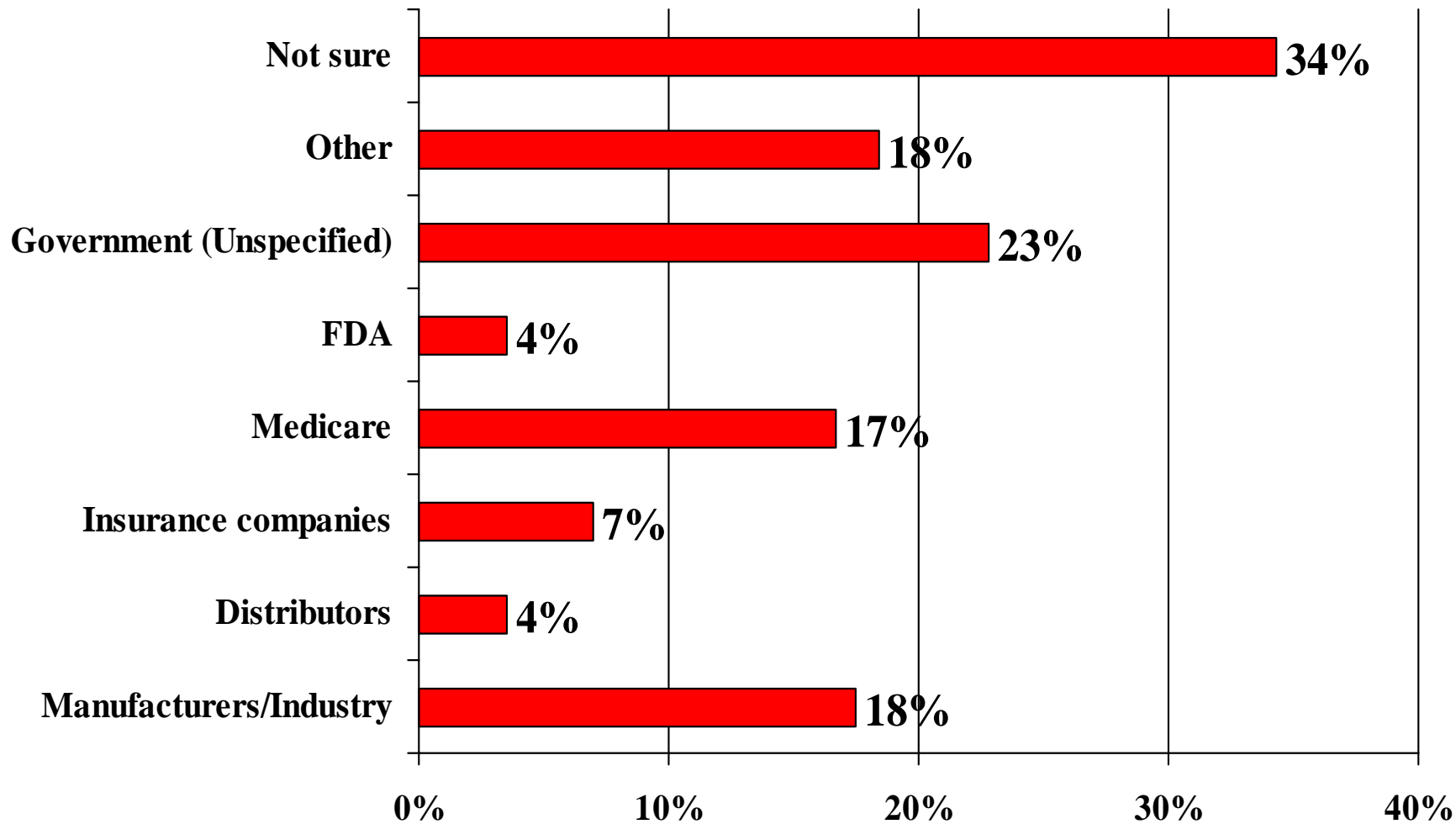


Q14c. Have these problems getting IVIG in the past 12 months had any negative effects on your health?

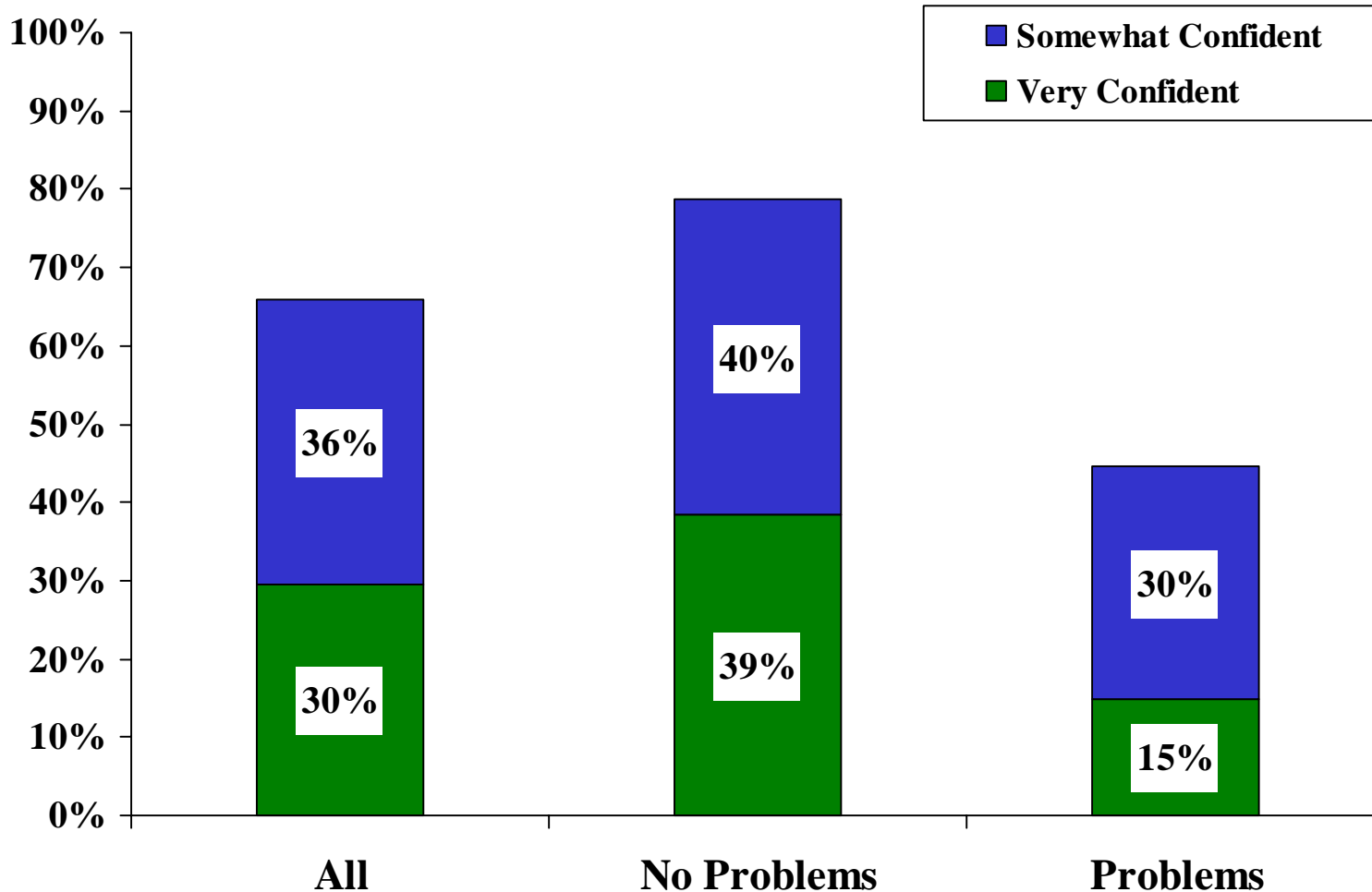
Negative Health Effects

- **Before I went to Criticare, I went to another hospital for treatment and they gave me the wrong kind and I had little spots on me. I had a really bad reaction and they (the doctors) mentioned kidney failure**
- Constant infections: skin infections, bronchial infections, a stomach infection, severe joint pains and fatigue so bad you could hardly lift your head off the pillow
- Feel worse: low-grade infections, sinus problems, pneumonia, it's related to what I'm getting and the frequency, because they were switching products on me
- I've been coming up with more respiratory infections and also I have suffered after effects from the gamma because it's not the brand that i normally take.
- I begin to have dysentery in which i tend to get infections in the intestinal and stomach areas.
- I got sick in mid February with a flu like that and i still have the cough to this day. It goes from yellow sputum to clear, it depends on whether I've had antibiotics or not. I had a problem with the hospital where I'm getting the gamma.
- I was supposed to go on field trip with kids but can't because of breathing problems and on airesol. A lot of flu and asthma attacks, my joints hurt when IGG's are low, headaches, all round sick
- In the past 2 months I've had to go 22-25 miles one way to a medical center in a different town where they didn't appreciate having someone from another town, The nurse didn't like my having emlacream on my hand and wrist
- Infections (sinus & bronchitis & pneumonia) & my disability from the joint pain when my level's are low is 'pretty overwhelming'
- Right now I'm in the middle of 8 or 9 weeks without the treatment because of ability to pay and I'm struggling, I'm very sick without it: recurrent shingles, extreme fatigue, joint pain.
- Sick all the month of January after the infusion. Not sure if they gave me the right treatment
- Uti & sinus infects & common infects & I was on antibiotics a lot & i have no energy & have to stay away from people to avoid catching anything
- I ended up w/secondary infection (respiratory/sinus) after rx was postponed

Who is Responsible for Problem in Getting IVIG

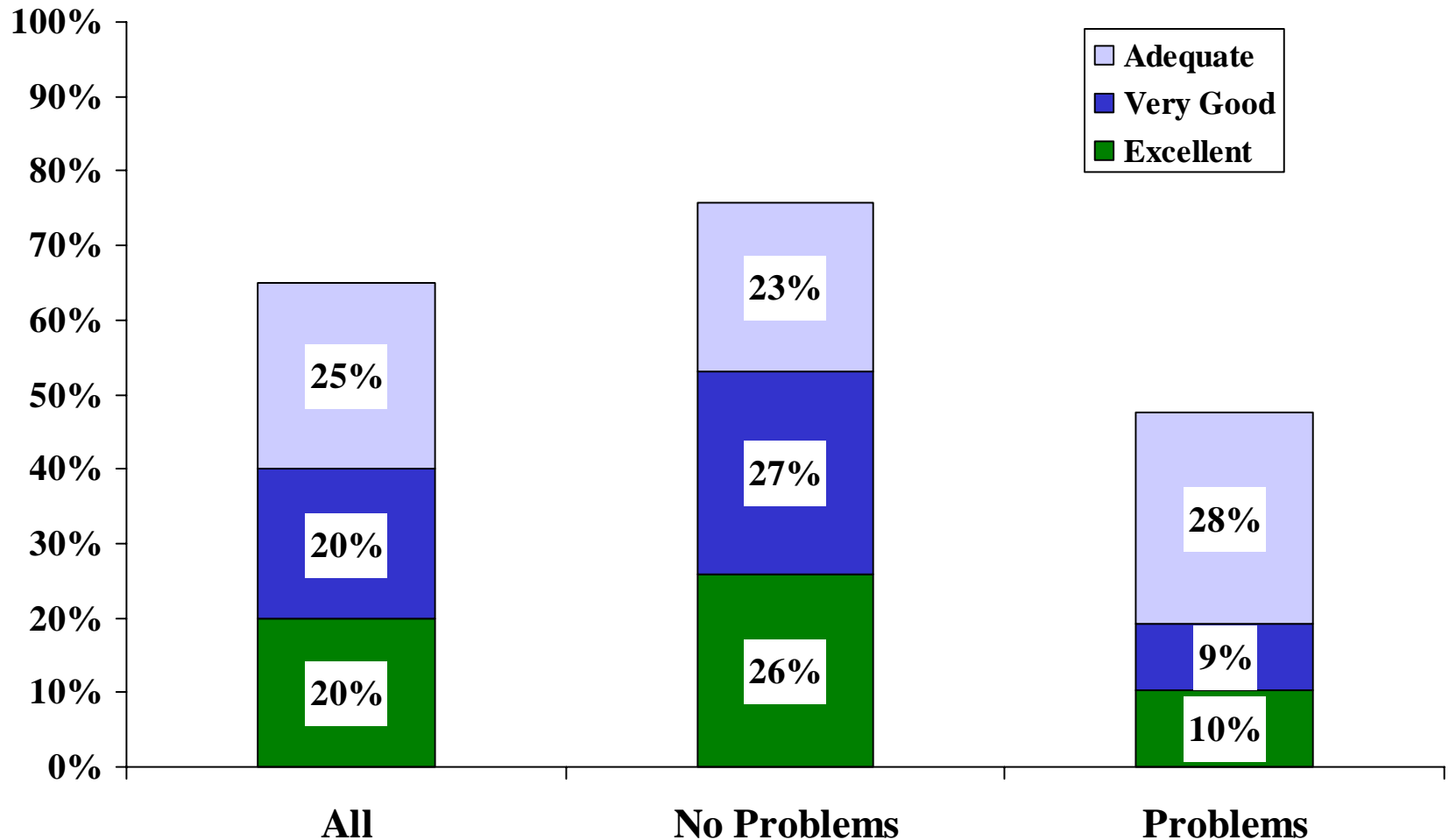


Confidence in Future Treatment by Experience with IVIG Problems



Q12. How confident are you that (you/he/she) will be able to have a dosage and infusion level necessary to keep (you/him/her) healthy in the future – very confident, somewhat confident, not too confident, not at all confident? 19

Rating of US Health Care System by Experience with IVIG Problems

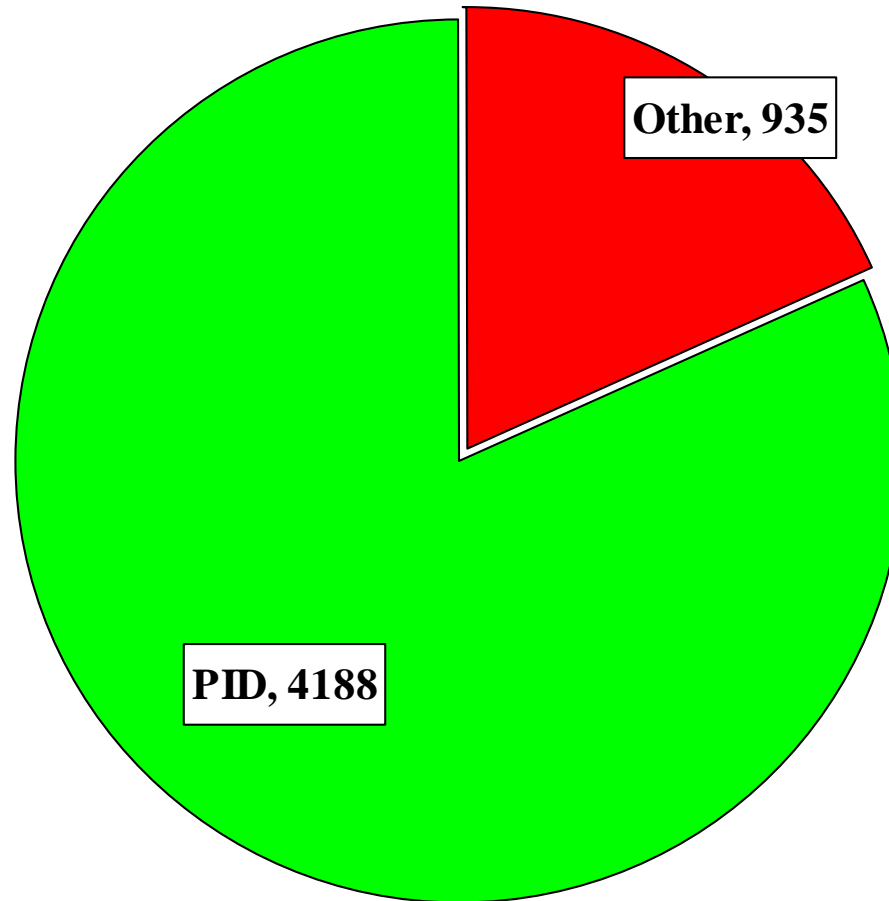


Q17. How good a job do you feel that the U.S. health care system is doing in getting proper treatment for (you/him/her) --- excellent, very good, adequate, less than adequate, poor or very poor? N=202

IDF Survey of Physicians: 2005

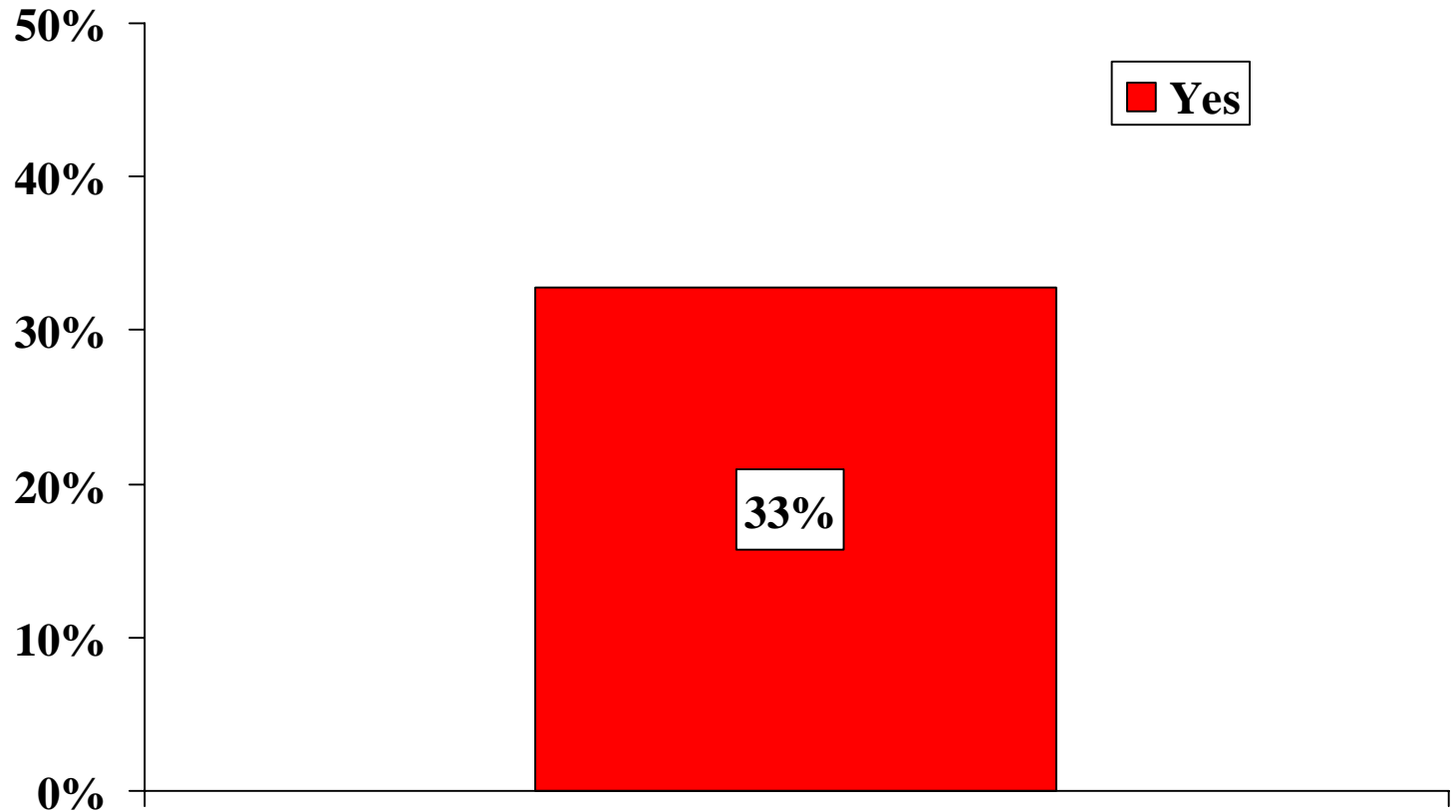
Faxed to a national sample of 558
physicians reporting PID patients
in IDF 2003 Physician Survey

Number of Patients Treated with IVIG



Q2. Approximately how many patients do you see who receive IVIG therapy for a primary immune deficiency disease, how many receive IVIG for something else?
N=287 with IVIG using patients

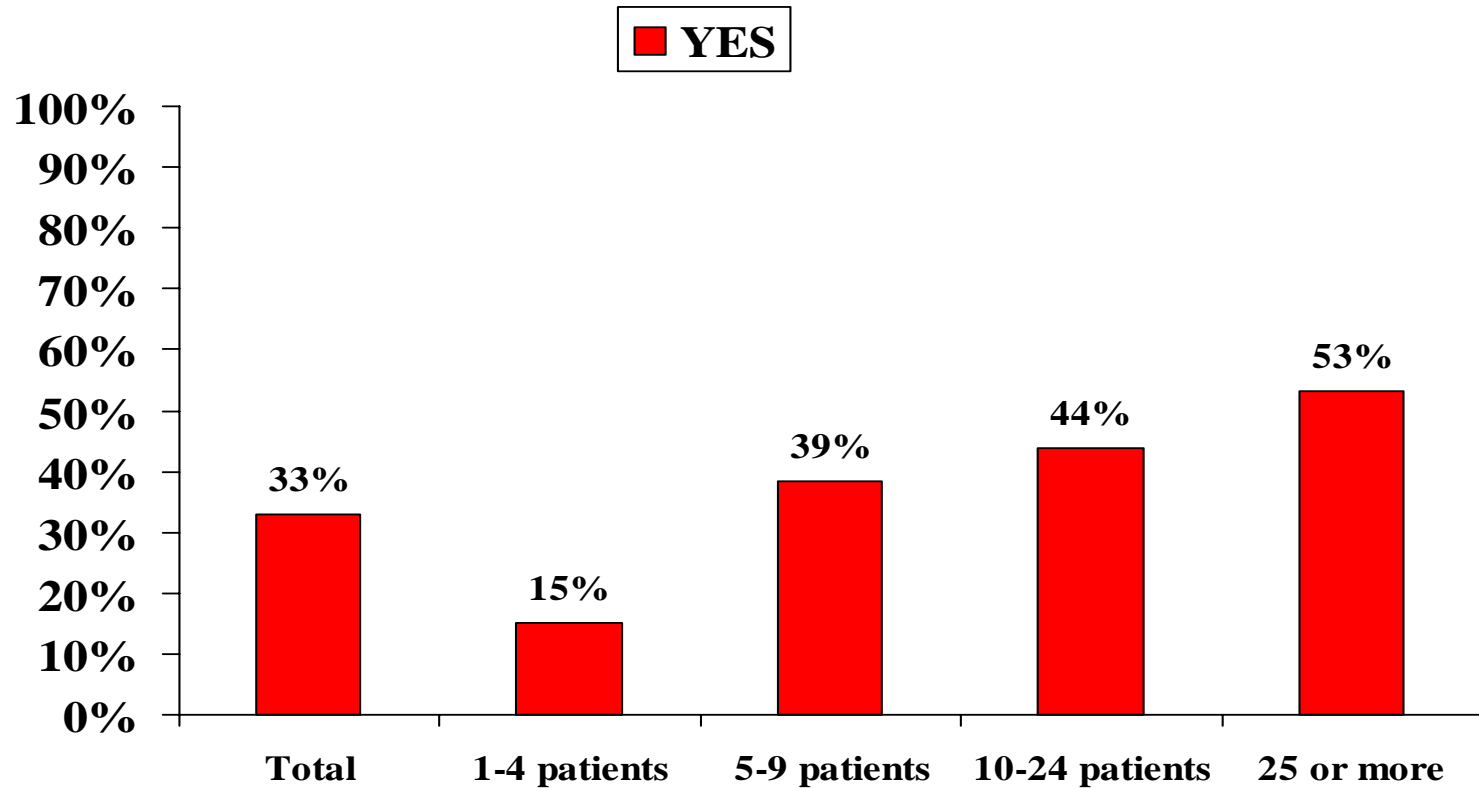
Significant Difficulty in Obtaining IVIG Products for Patients since 1/1/05



Q3. Since January 1, 2005, have any of your patients experienced any significant difficulty in obtaining IVIG treatment as a result of REIMBURSEMENT FOR TREATMENT rather than supply?

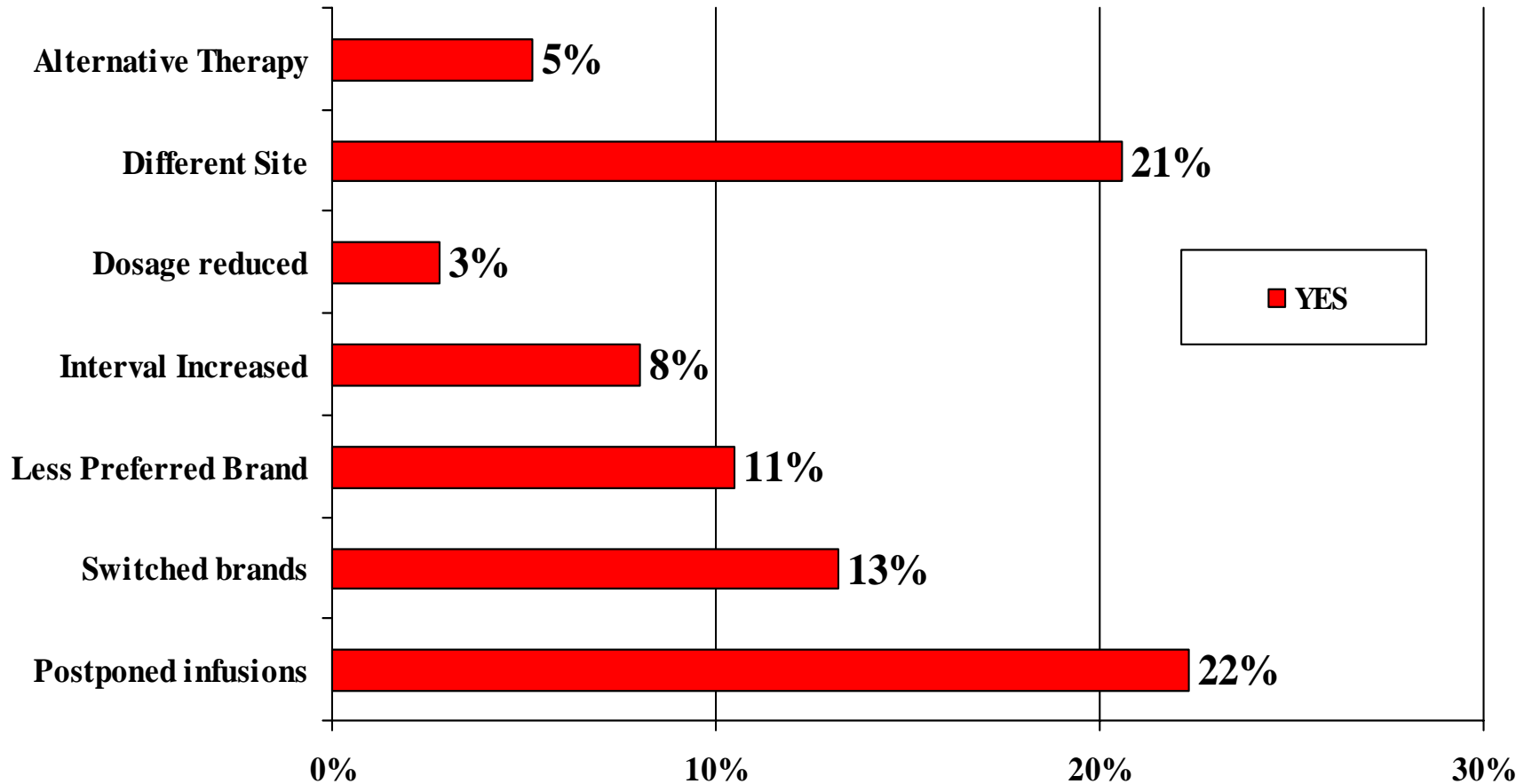
N=287 doctors with IVIG patients

Significant Difficulty in Obtaining IVIG Products by Number of PID Patients



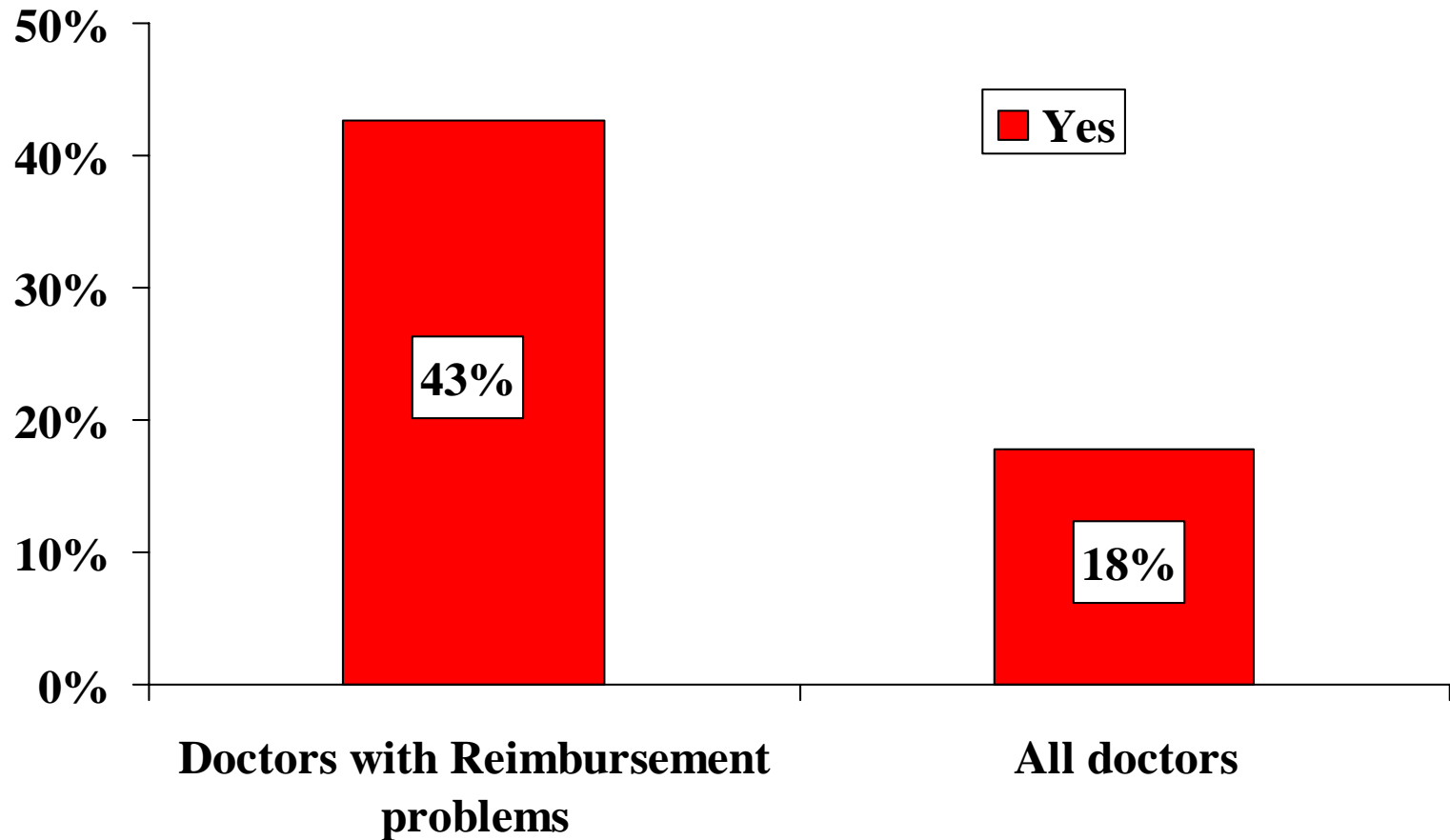
Q3. Since January 1, 2005, have any of your patients experienced any significant difficulty in obtaining IVIG treatment as a result of REIMBURSEMENT FOR TREATMENT rather than supply?
N=285 doctors with IVIG patients

Patient Impact of Problems of Availability



Q5. As a result of problems of REIMBURSEMENT for IVIG since the beginning of the year, which of the following (if any) has happened to your patients? N=285 Doctors with IVIG using patients

Adverse Health Effects on Patients as a Result of Availability of IVIG



Q6a. Since January 1, 2005, have problems of availability or access to IVIG supply had any ADVERSE EFFECTS on the health of any of your patients? N=287 doctors with IVIG patients