



Patient's understanding of the potential side effects, effectiveness and required safety monitoring of their current disease modifying therapy

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Method



- Scripted phone call to all patients who have had Alemtuzumab within the past 3 years

Questionnaire



1) How happy are you with your understanding of potential side effects of Alemtuzumab on a scale of 1-10 ? (with 10 being very happy and 1 being not happy)

2) What sources would you use if you wanted to get more information about your disease modifying therapy ?

3) What potential side effects of Alemtuzumab do you recall ?

- *Record answer and Prompt following*
- 3a) At the time of infusion ?
- 3b) Long term potential side effects or risks

Questionnaire

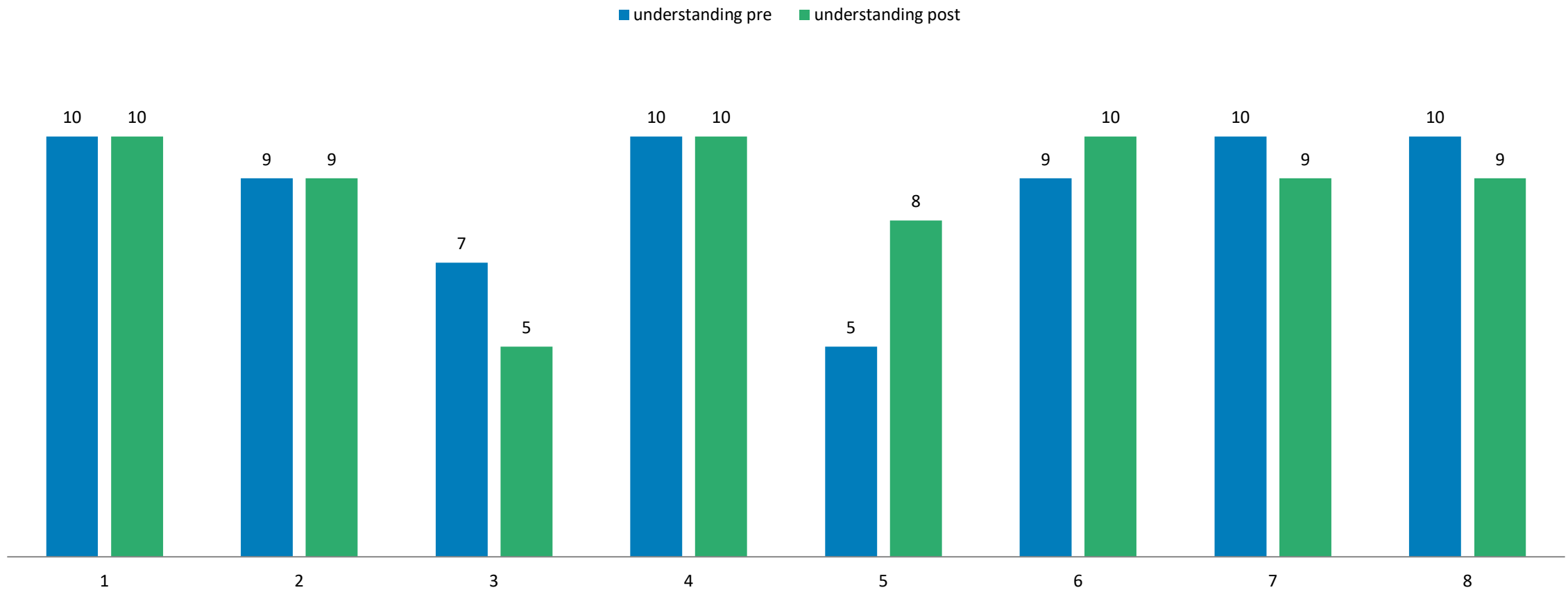


- 4) What safety monitoring do you require when on this treatment ?
- 5) What potential complications are we monitoring for ?
- 6) How effective do you feel Alemtuzumab is on a scale of 1-10 (10 being the most effective) ?
- 7) How risky do you feel Alemtuzumab is on a scale of 1-10 (10 being the most risky/ life threatening) ?

Results



patient happiness on understanding potential side effects

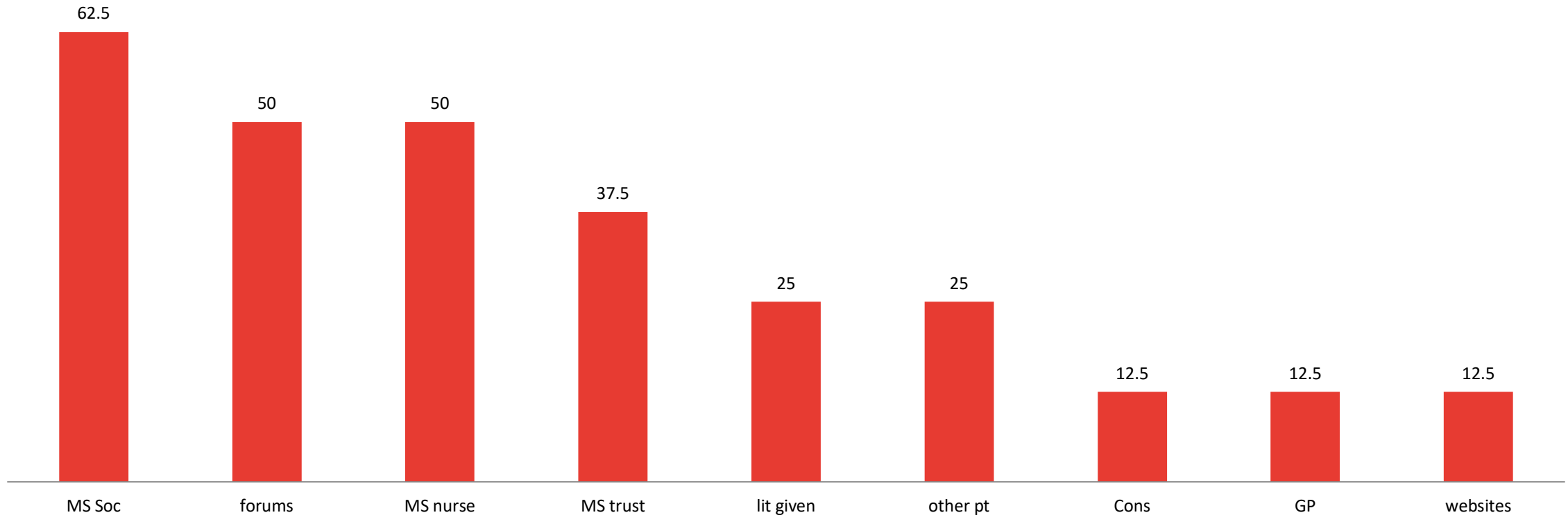


Sources of information



percentage of patients who mentioned the following as sources of information

percentage



Patient perception of side effects during infusion



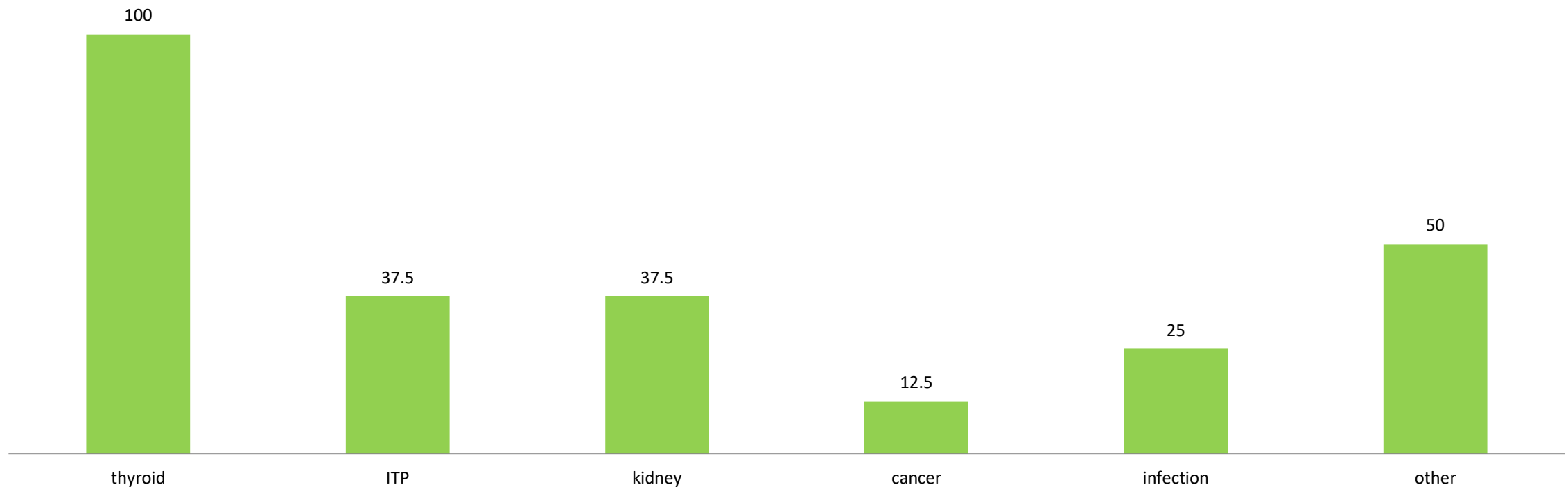
patient number	Side effects during infusion
1	increased heart rate, rash, dizzy
2	rash, increased heart rate and temperature
3	rash, increased heart rate and blood pressure
4	Anaphylaxis, changes in blood pressure and temperature
5	thyroid, herpes, kidney and liver problems
6	rash, flushing, infection
7	Side effects of steroids, anaphylaxis, changes in BP and temp
8	rash

Awareness of long-term complications of Alemtuzumab



Awareness of long-term complications of Alemtuzumab

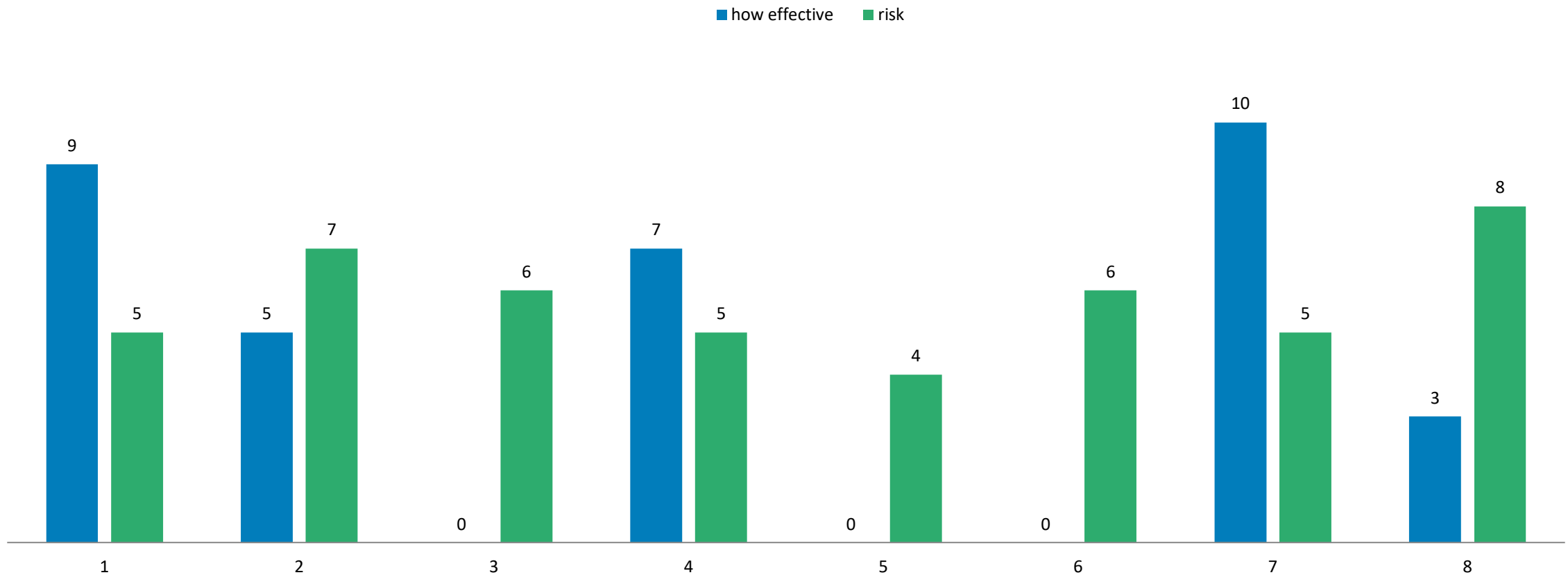
percentage



Patient perception of effectiveness and risk



patient perception of effectiveness and risk of Alemtuzumab treatment



Conclusion and how it will influence practice



- Source
- Side effects
- Monitoring
- Perception of risk and effectiveness

Practice points



- Other patient's opinions and personal experience seem to have more influence than previously thought. May be even more influential than a health professional's opinion.
- “ auto immune conditions” could be quite vague for the patient. Specific examples may be useful.
- Perception of risk is individual and would be useful to check patient's perception at the time of consenting

Questions ?....



- Thank you