

Sarcoma Patient Experience Survey 2011/2

CSCCN SARCOMA GROUP

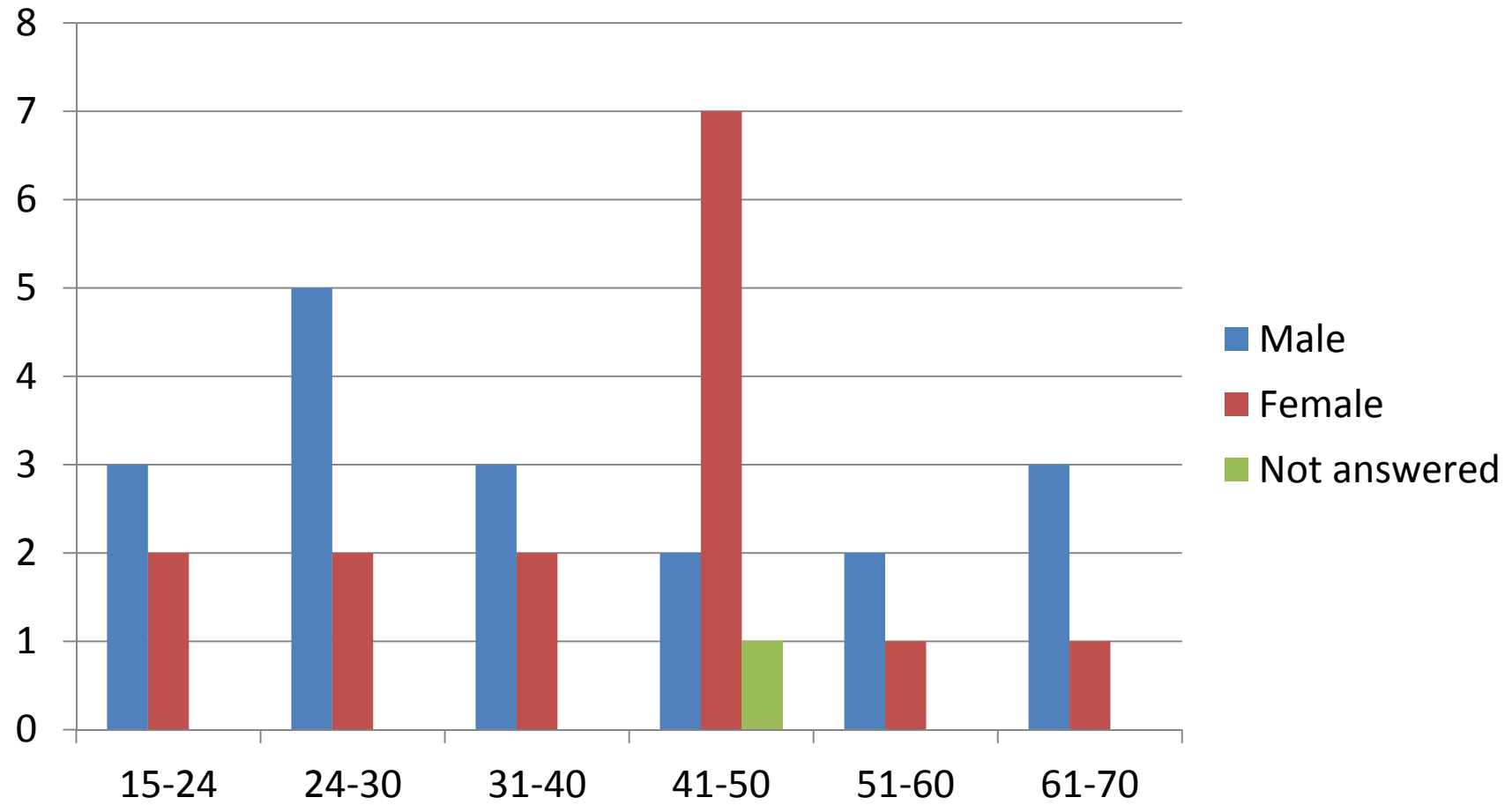
Sarcoma Patient Experience Survey

- First survey
- Developed by 2 patient reps supported by CNS Louise Sharif and Patient and Public Involvement Lead Helen Eggleton and with the help of the members of the Sarcoma South UK Support Group and Cancer Research Group.
- 50 surveys given out to patients at sarcoma OPD

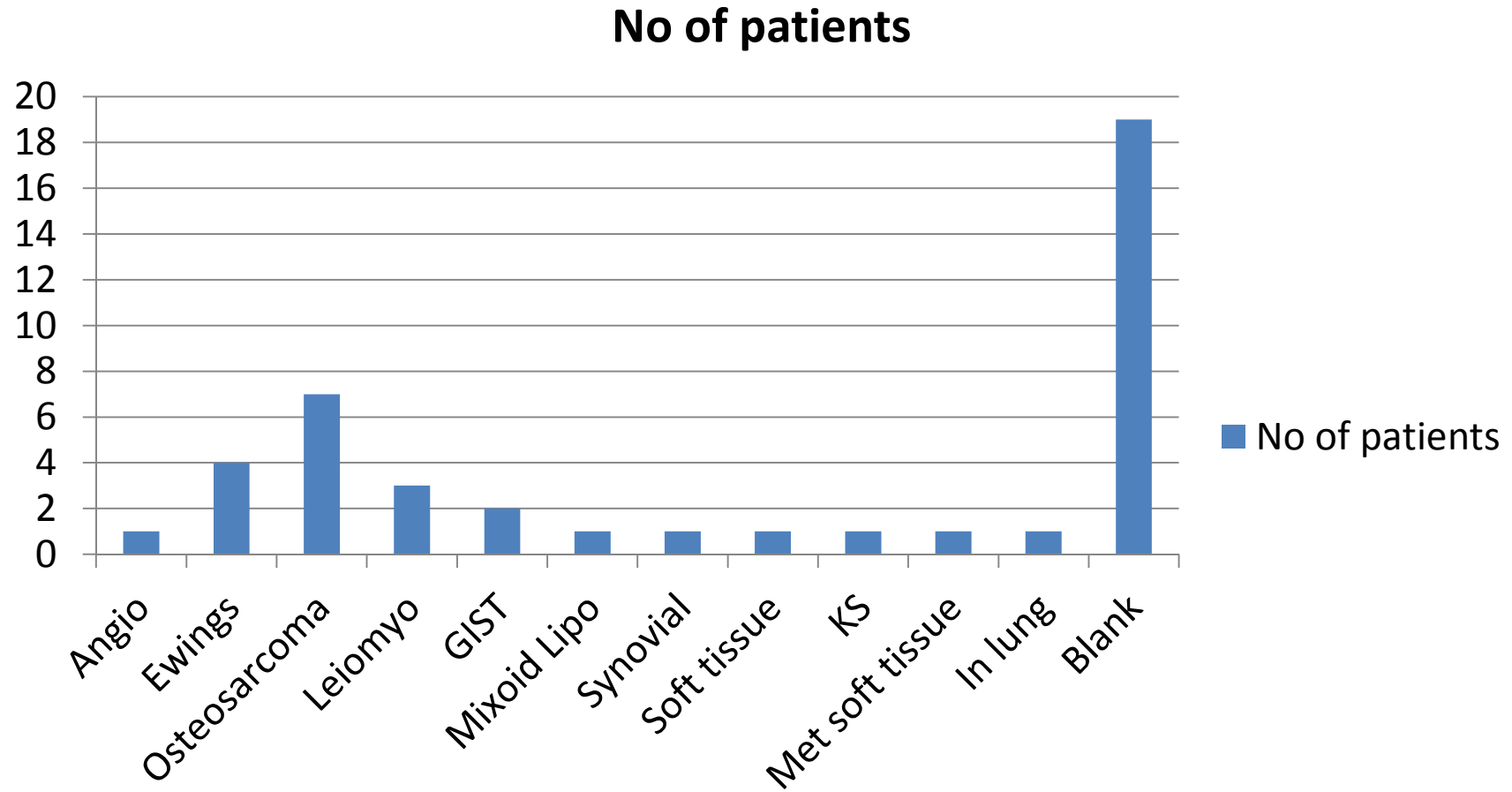
Results

- 78% response rate (39 out of 50 surveys)
- 56% male; 41% female
- 41% Soton postcode
- 23% Portsmouth/IOW
- 15% Bournemouth
- 8% Farnborough; 8% Salisbury

Age



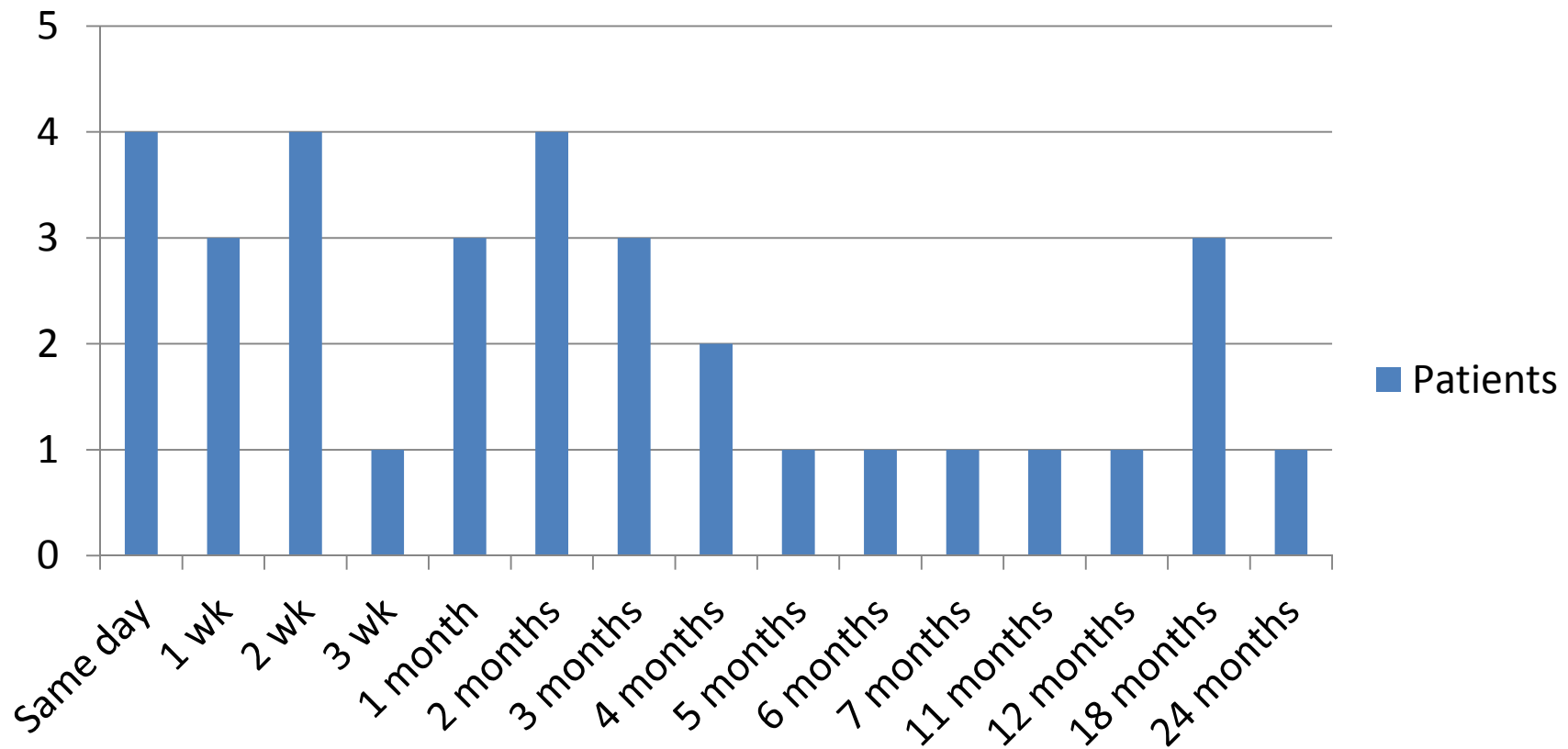
Type of sarcoma



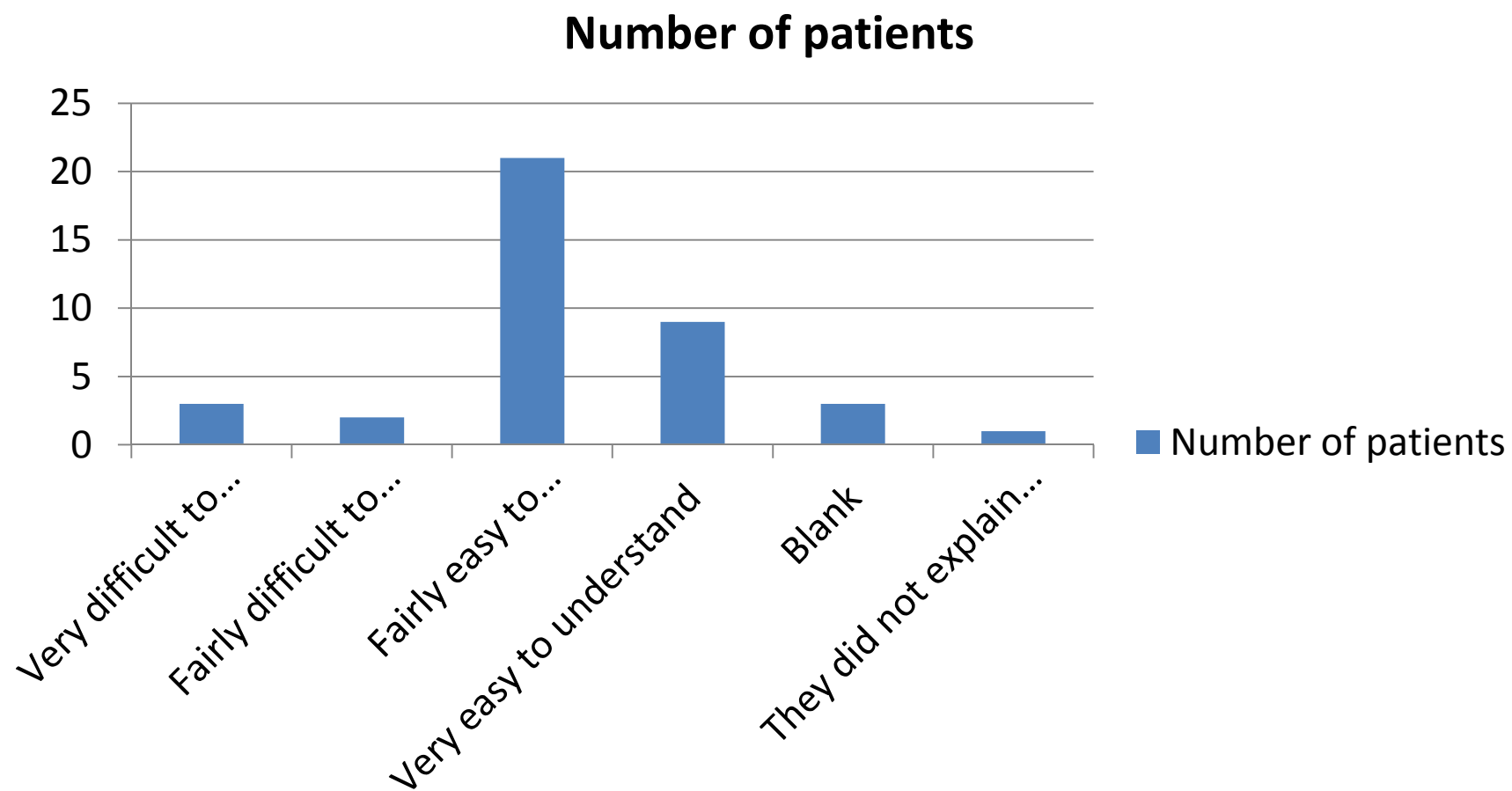
After seeing GP with symptoms how long did it take to be referred to hospital?

Mean 19.5 weeks; Median 8 weeks

Patients

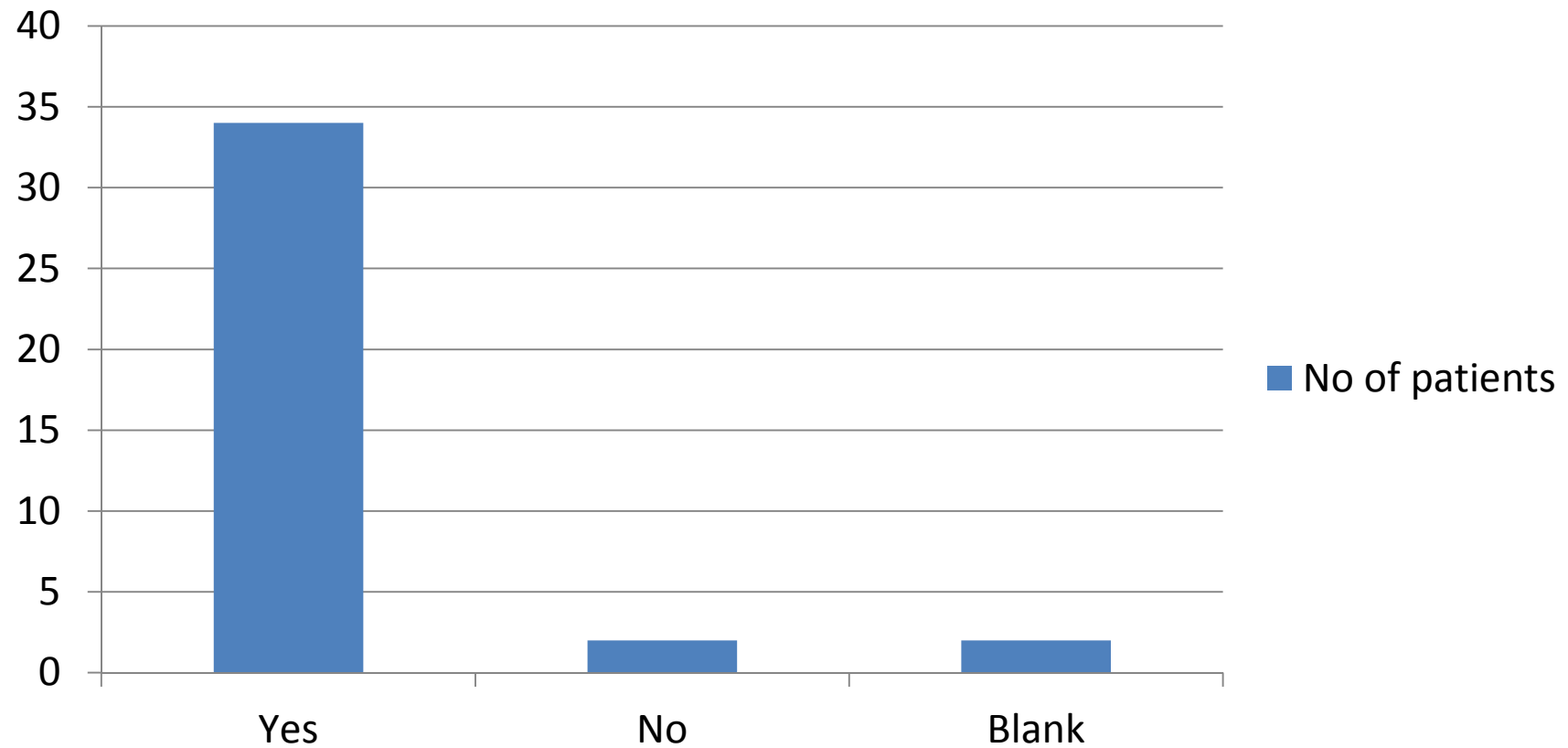


Was the diagnosis of sarcoma explained in way that was easy or difficult to understand?

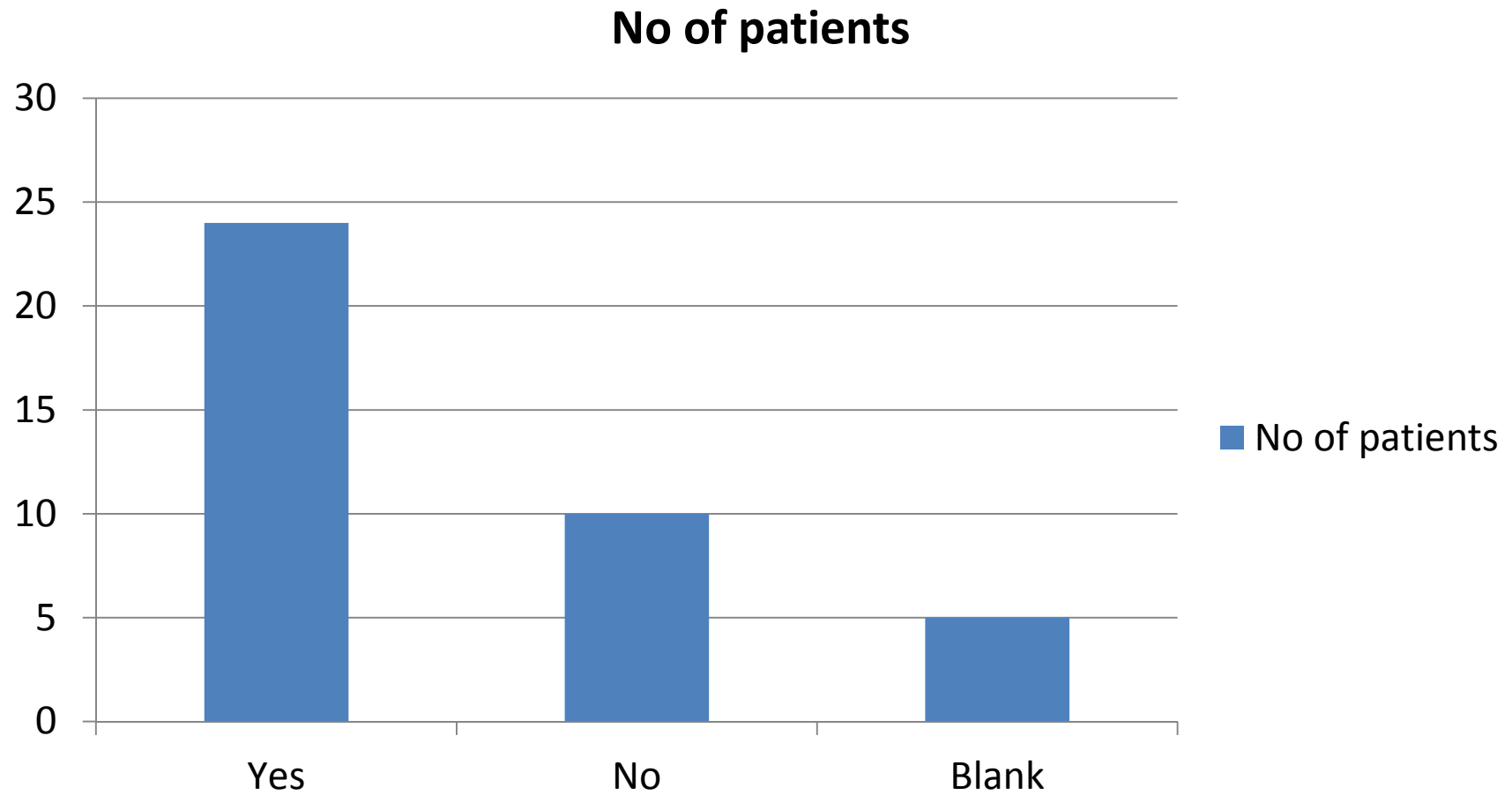


Did you feel able to ask questions about your diagnosis and treatment?

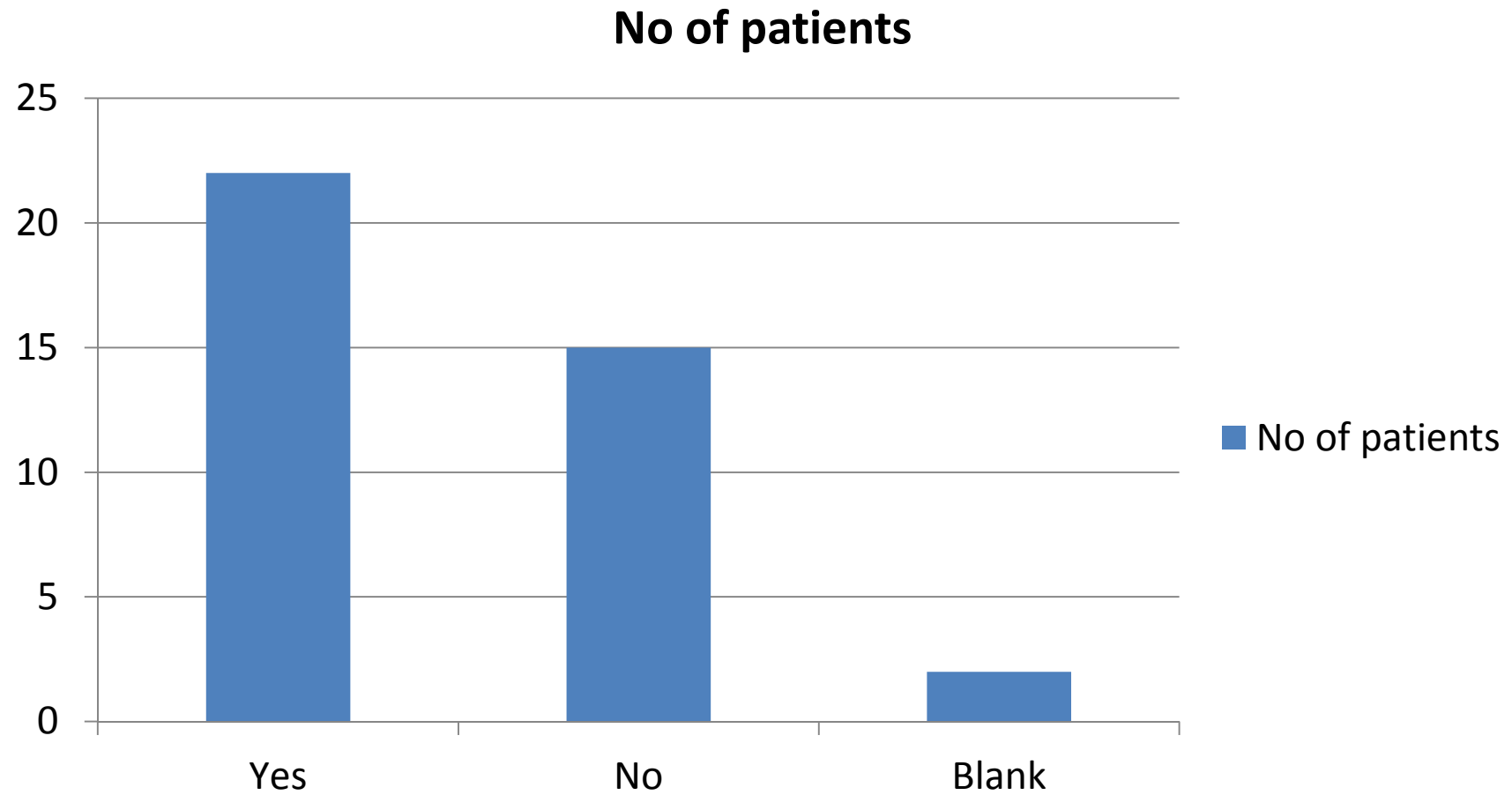
No of patients



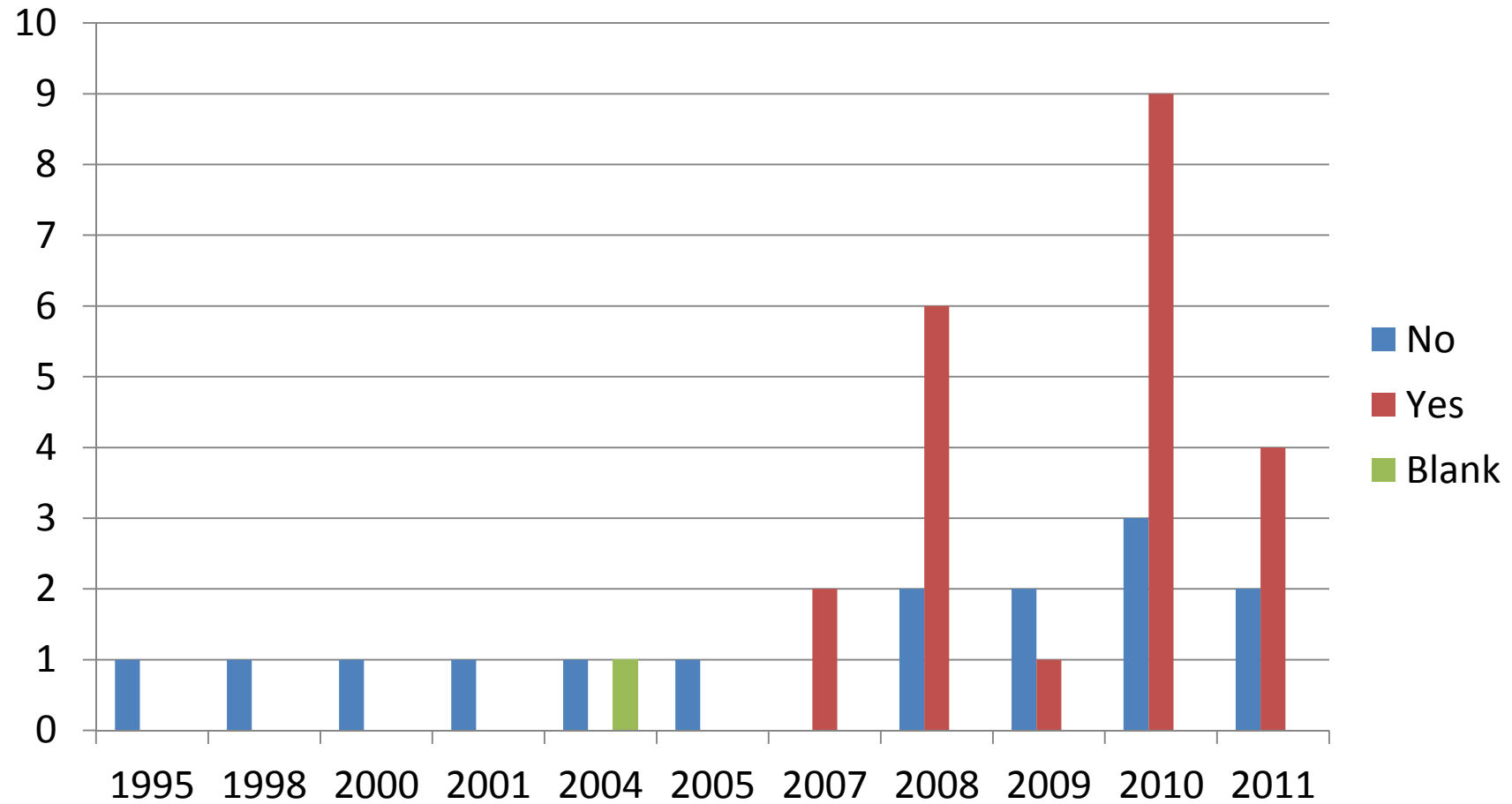
Did you feel that you were offered sufficient time to discuss your emotions and feelings?



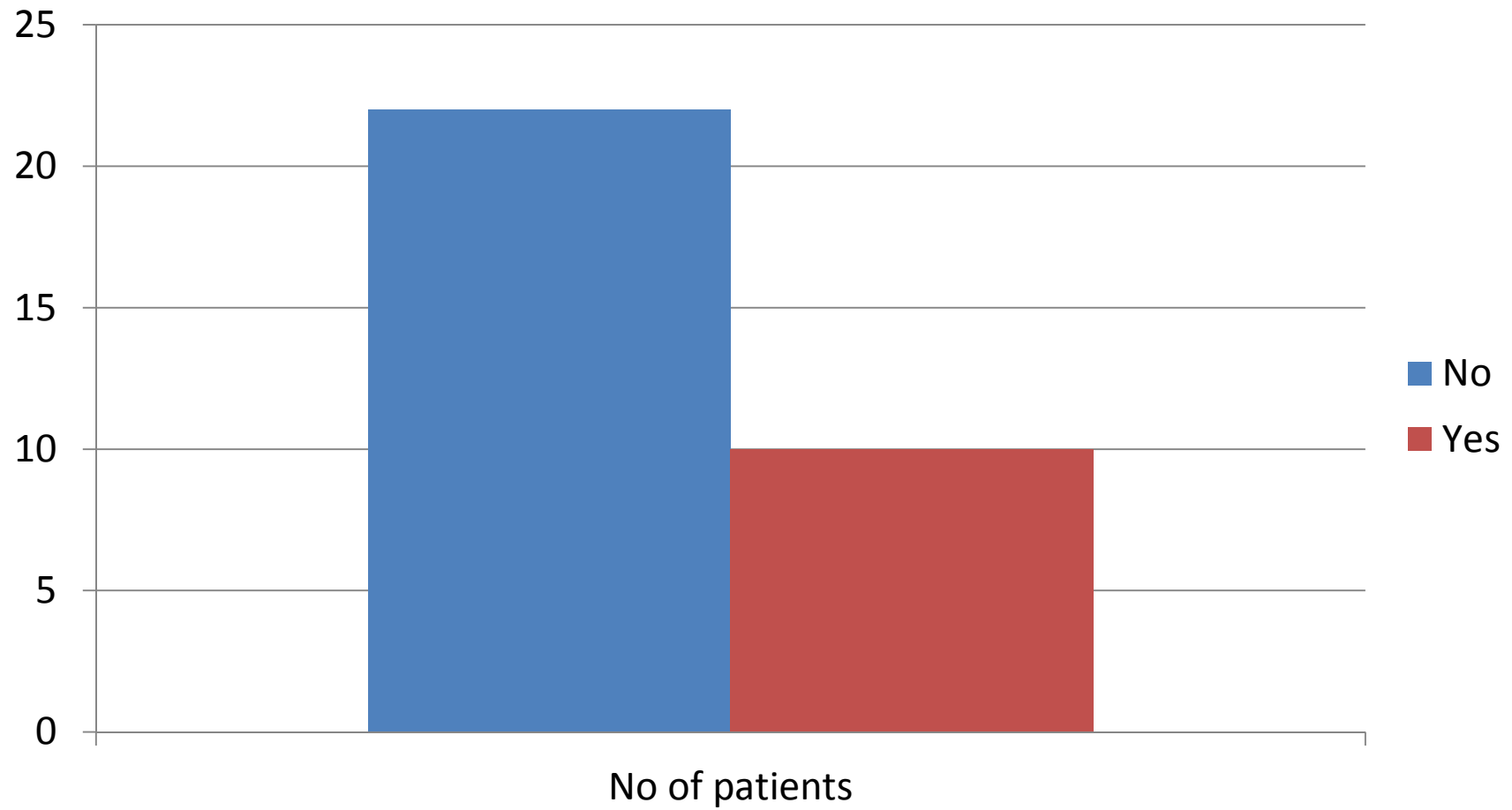
Were you given the name/telephone number of a health care professional (known as a “Key Worker”)?



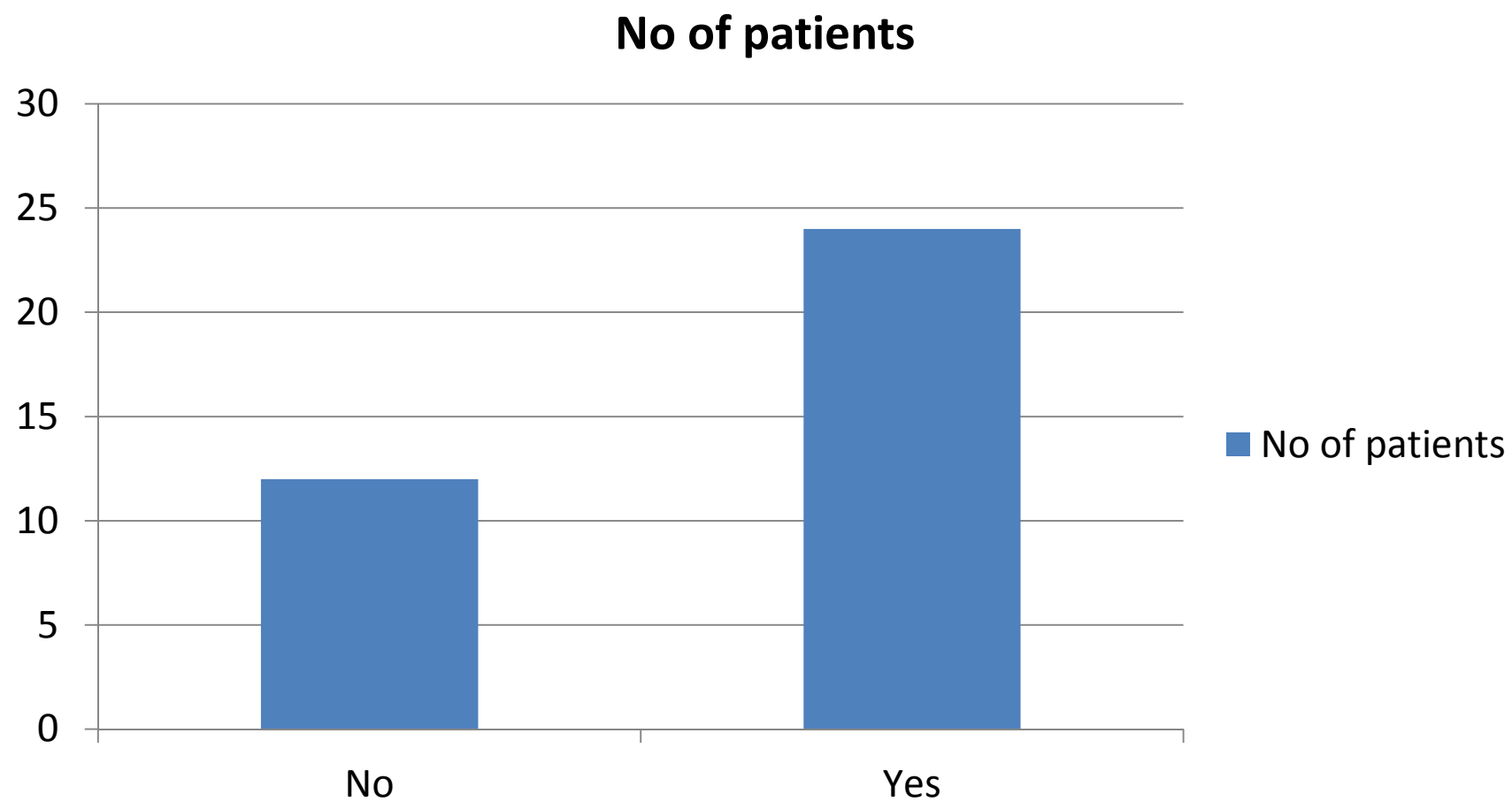
Keyworker details by year of diagnosis



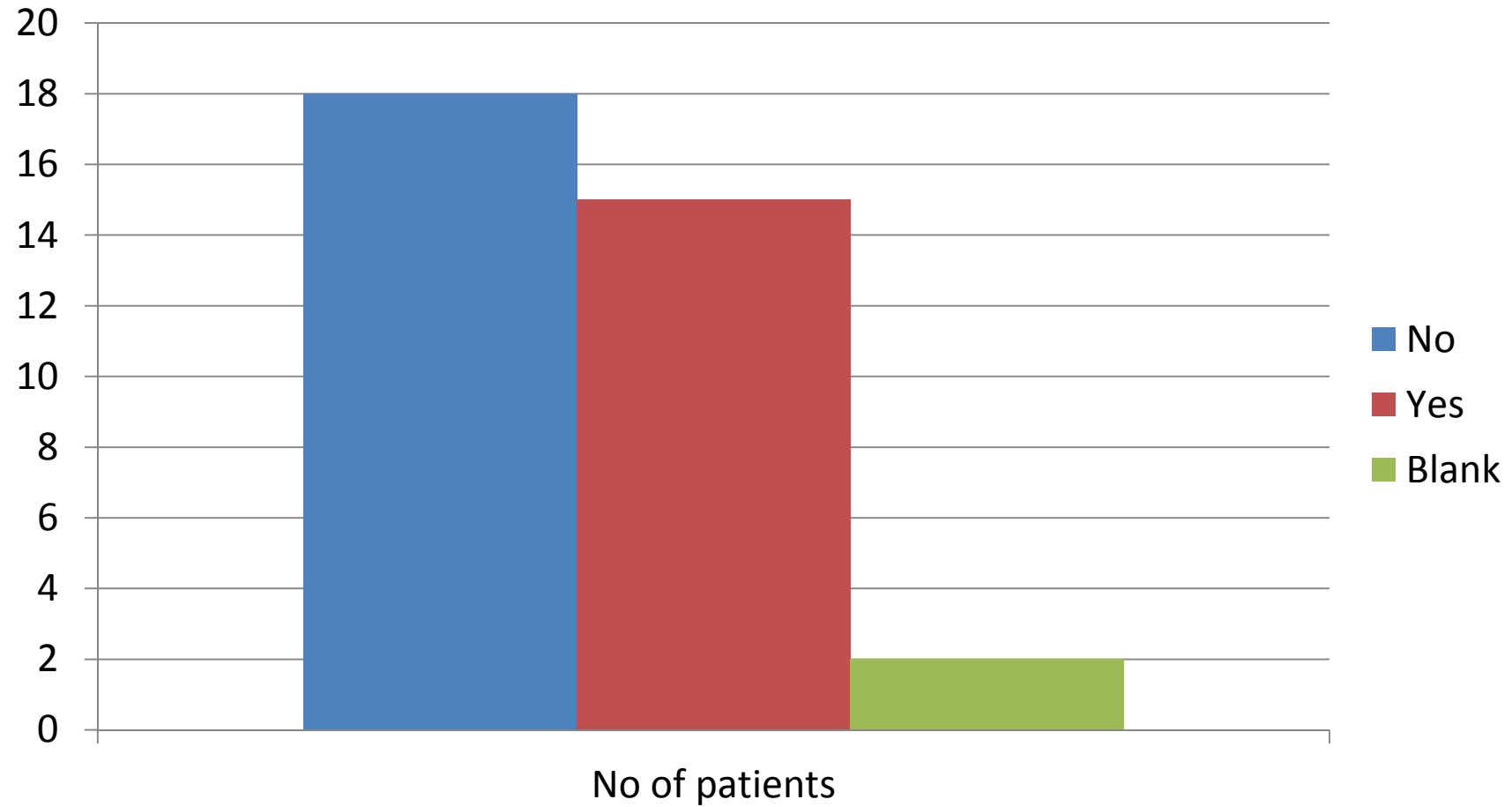
Were you offered copy letters from Consultant to GP?



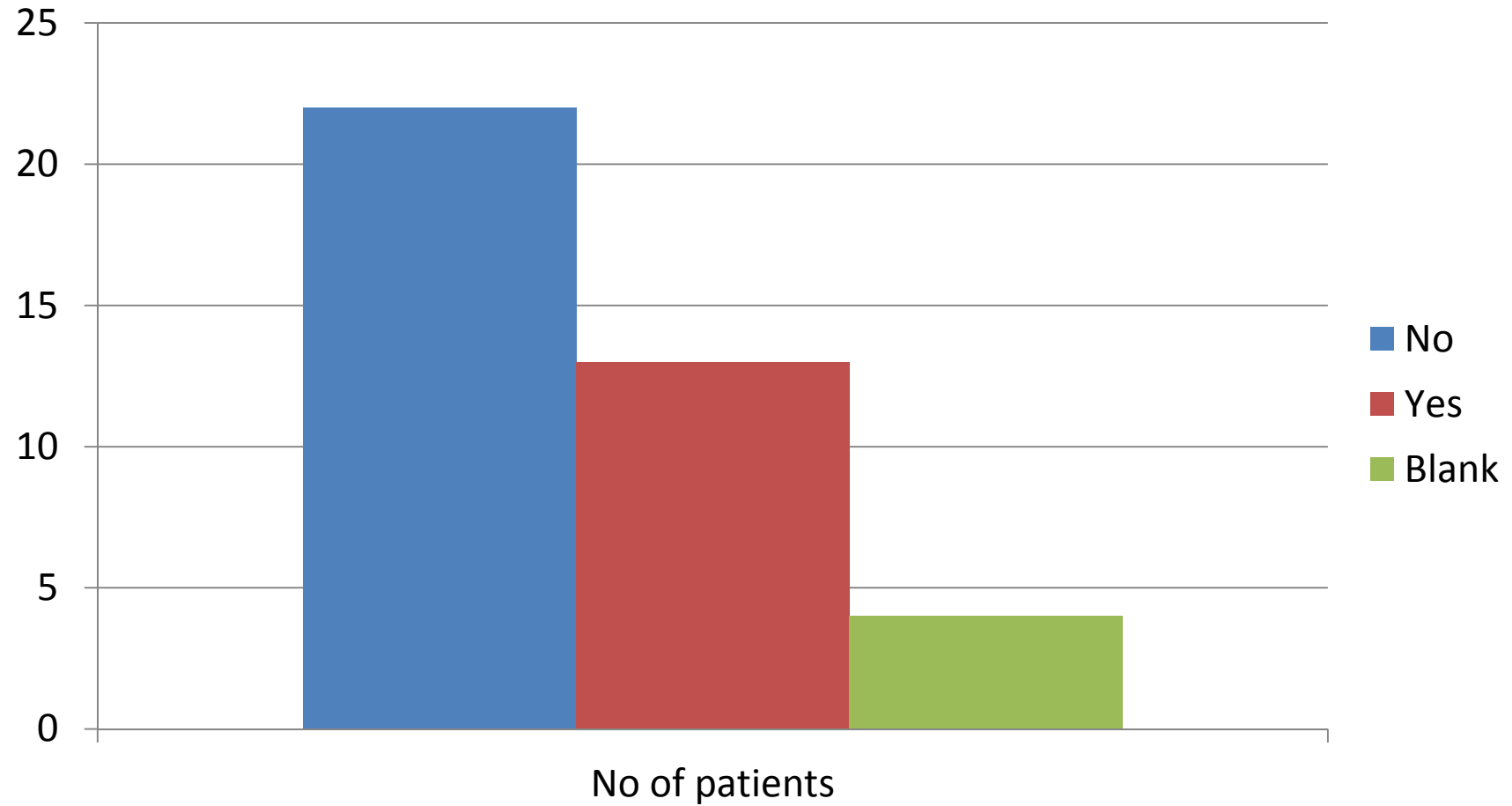
At diagnosis were you offered printed information about sarcoma and treatment?



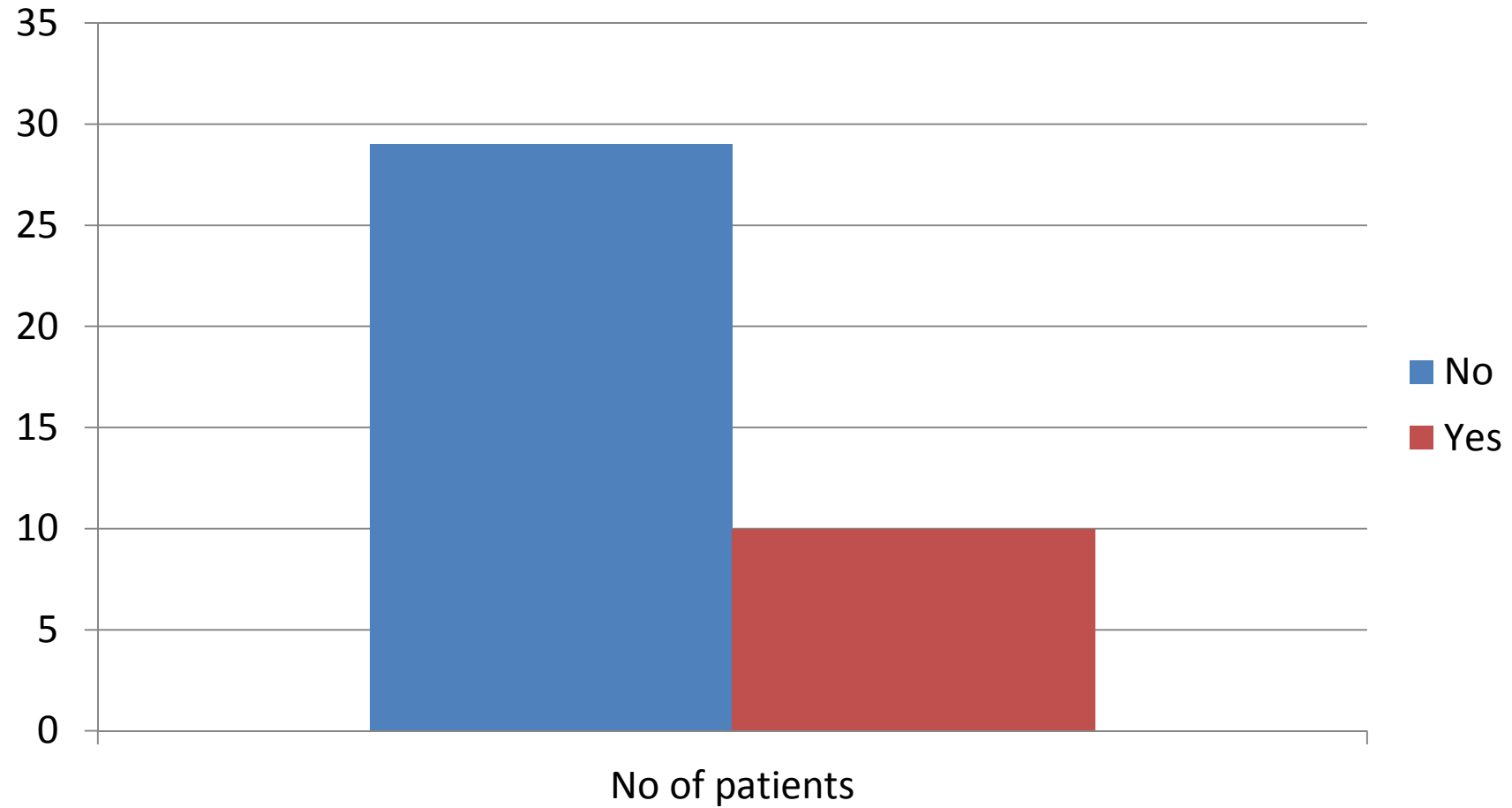
Were you told about the sarcoma support group?



Were you given a support group leaflet?



Any difficulties travelling to hospital for appointments/treatments?



Comments

- “I have been extremely happy with my consultant and his team with a special mention to the CNS who has been a fantastic support to my wife and I.”
- “It is the diagnosis by non-specialist that was so upsetting and would not wish that on anyone”
- “It would have been helpful to have known about the sarcoma support group straight away, as I felt quite isolated.”

Actions

- Address issue of delayed referrals to secondary care, liaise with CSCCN LAEDI; GP Education Day
- MDTs need to provide written information on sarcoma and support groups to patients and carers
- MDTs need to give the patients the opportunity for copy summary/letter
- Next survey to include question on research