

CSCCN SARCOMA PATIENT EXPERIENCE SURVEY 2011/12

Summary

Background

In 2010 the Network Sarcoma Group agreed to undertake a patient experience survey, the first one for sarcoma patients. The survey questions were to be developed by the group's two patient representatives with support from the CNS Louis Sharif and Patient and Public Involvement Lead Helen Eggleton. Patients and carers from the Sarcoma South UK Support Group met for a focus group and feedback from their experiences helped generate the survey questions.

Aim

To obtain feedback on sarcoma patients' experiences of care and services.

Method

The draft survey was reviewed and further developed by the Cancer Research Group. 50 surveys were given out to patients attending sarcoma outpatient clinics at Southampton University Hospital Trust (SUHT). Completed surveys were sent to Helen Eggleton for analysis.

Results

- Overall response rate of 78% with 39 completed surveys returned.
- 48.7% (19) could not name their type of sarcoma. (Q4)
- The time from seeing their GP with symptoms to being referred for first appointment at hospital ranged between same day up to 104 weeks. The average time to be referred was 19 weeks with the median being eight weeks (Q5). 77% (30) rated the explanation of their diagnosis from very easy to fairly easy to understand. (Q7)
- 87% (34) felt able to ask questions about their diagnosis and treatment (Q8).
- 61.5% (24) felt that they were given sufficient time to discuss their emotions and feelings. (Q10)
- Only 56.4%(22) were given the name/telephone number of a health care professional (Q12).
- 56.4% (22) were not offered a copy of the letters between consultant and GP (Q13). Of those that said no 15 (68.1%) patients said they would have liked a copy.

- 61.5% (23) were offered printed information about sarcoma and its treatment (Q14). Of those that said yes, 21 patients found the information useful. Of the 12 patients that said they did not receive written information, over half would have liked to have been offered printed information.
- 56.4% (22) were not told about the sarcoma support group (Q16). However another 15.3 %(6) did not respond which may suggest they were not told or certainly could not remember being told.
- 56% (22) of all patients were not given a leaflet about the sarcoma support group (Q17).
- From the free text comments there was positive praise and gratitude to staff in general with several patients highlighting the value of the CNS. Communication issues and information giving were also raised as issues.

“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”

“Was taken into side room by Mr *** initially who was a surgeon, not sarcoma or oncology specialist. I was bluntly told I had a malignant tumour and that I was being melodramatic when asked how soon it would be cut out/removed.”

“From beginning to end the service I received was fabulous. All the staff and doctors were lovely – hats off to them.”

“I do not recall it being explained at all, other than I had cancer and this condition is very rare.”

“Any waiting to be hooked up to the chemo could take hours waiting. The longest was from 12.00 to 10.30pm!! This happened on more than one occasion.”

Network Group Discussion and Actions

- To address issues of delays in referral to secondary care: to liaise with CSCCN Local Awareness and Early Diagnosis Initiative Steering Group; GP Education Day
- Identify opportunities for patient and public awareness.
- Share report with The London and South East Sarcoma Network and Sarcoma Clinical Studies Group
- In line with National Peer Review Measures MDTs need to give patients the opportunity of a copy of a summary when diagnosis; treatment plan, follow up arrangements are discussed.
- MDTs need to provide written information to patients and carers on sarcoma and support groups.
- Next survey to include question on research.

Tricia Moate 26/10/12
Patient Rep