

BRAIN TUMOUR INFORMATION & SUPPORT

BRAINWAVES NI

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Regional Neuro-Oncology Service Information Evening

Ms Medb Bradley


Information Evening hosted by Brainwaves NI, in partnership with the Northern Ireland
Regional Neuro-Oncology Multi Disciplinary Team.



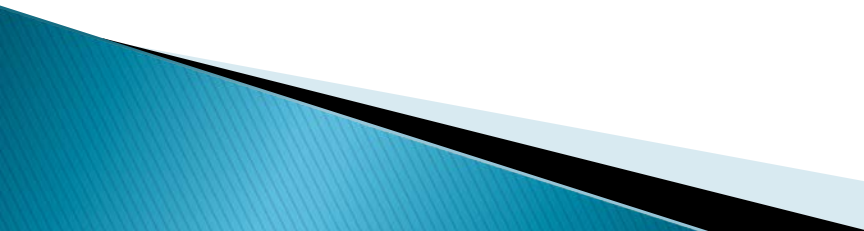
Neuro–Oncology Patient Experience Survey

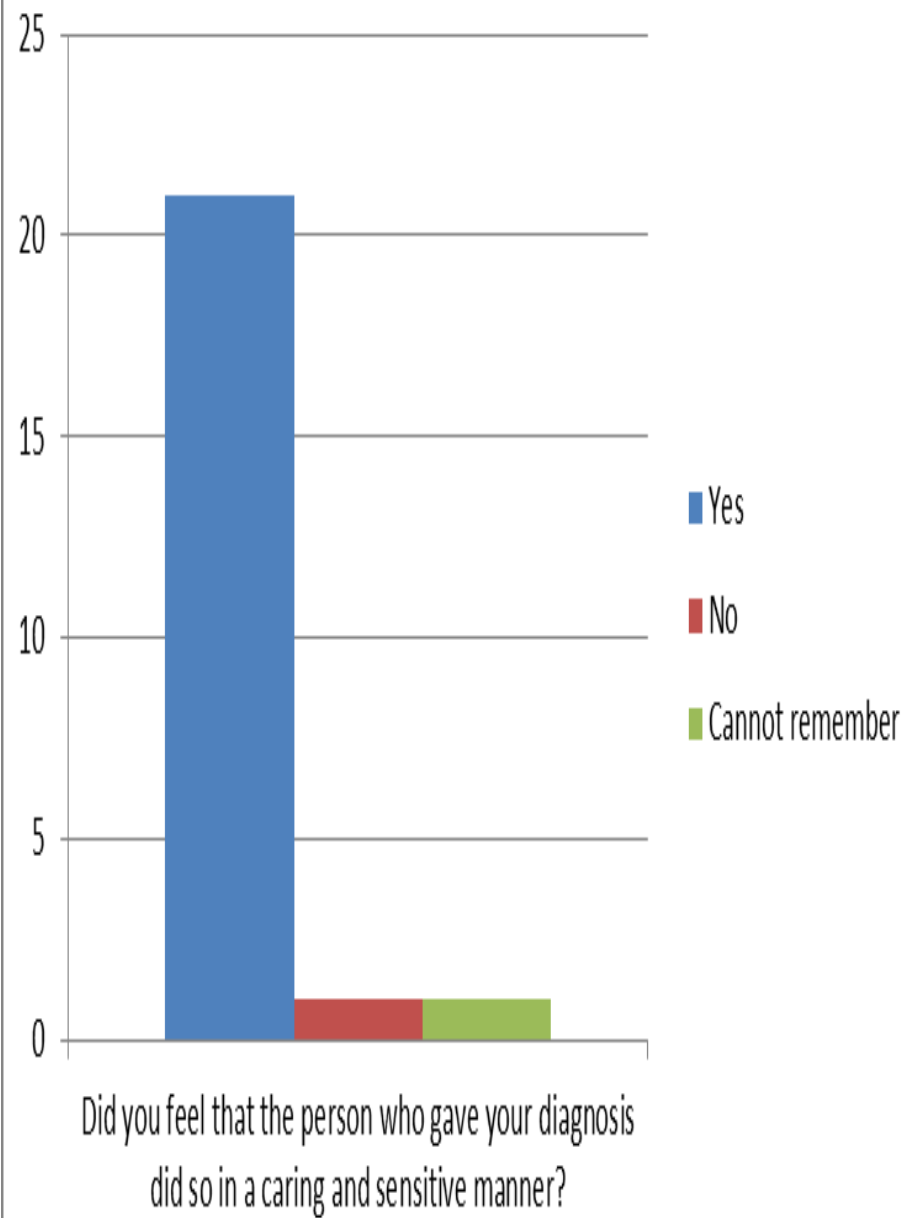
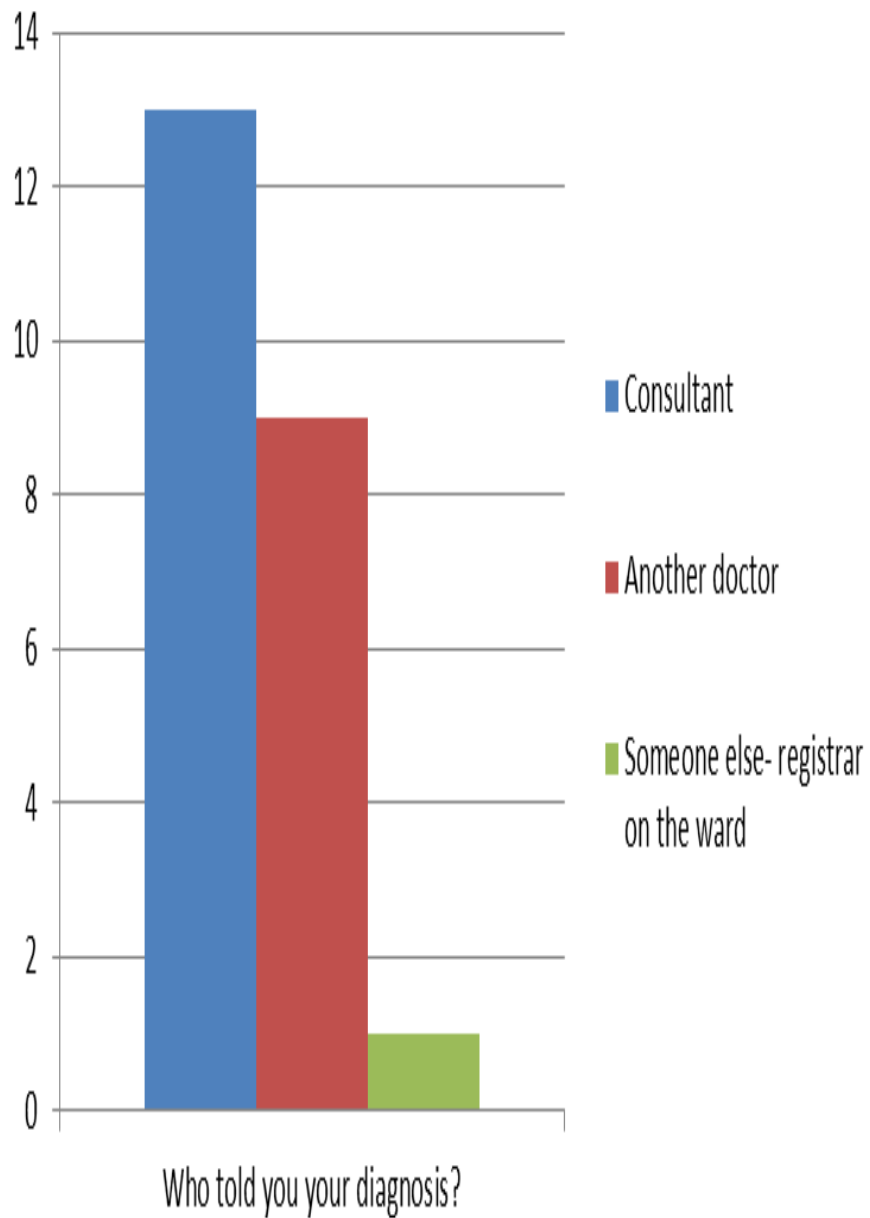
Medb Bradley Neuro–Oncology CNS
Belfast Trust

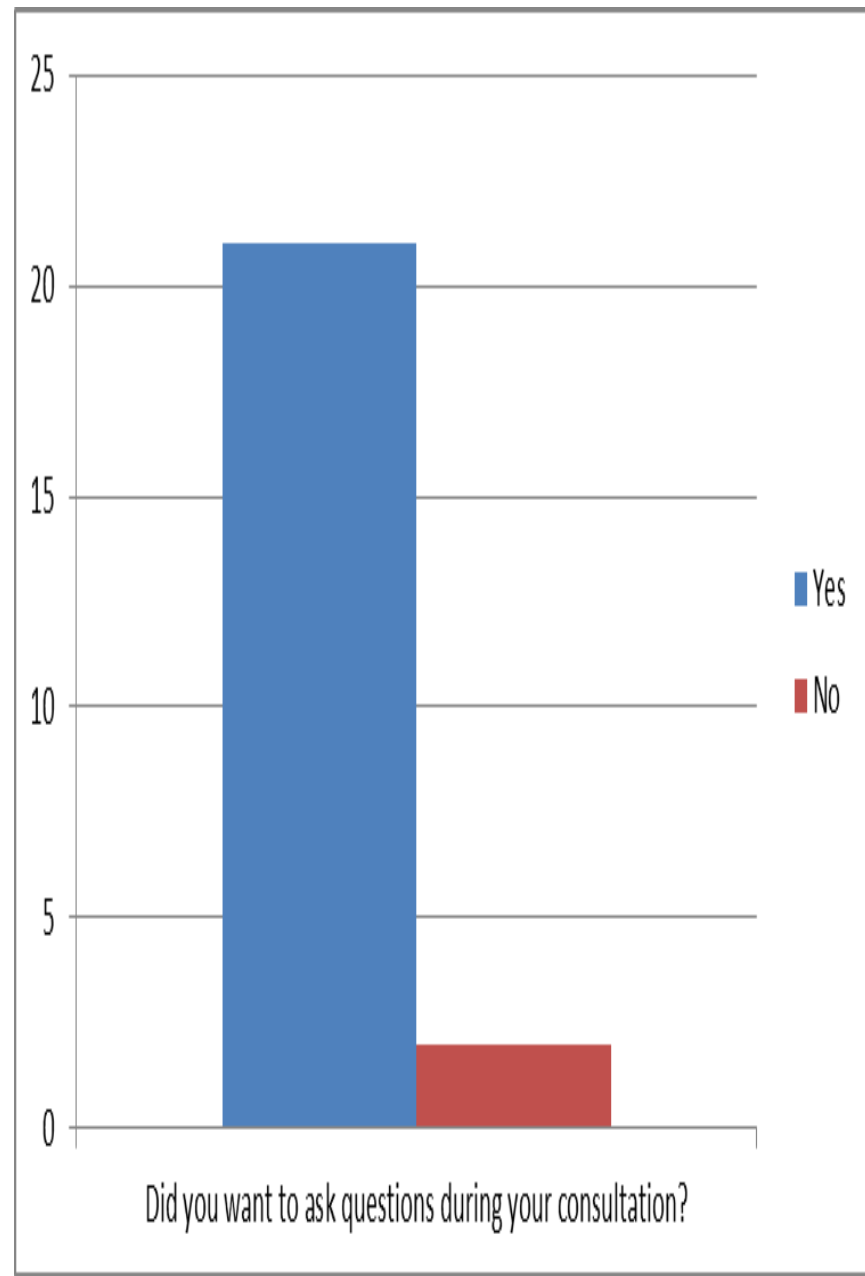
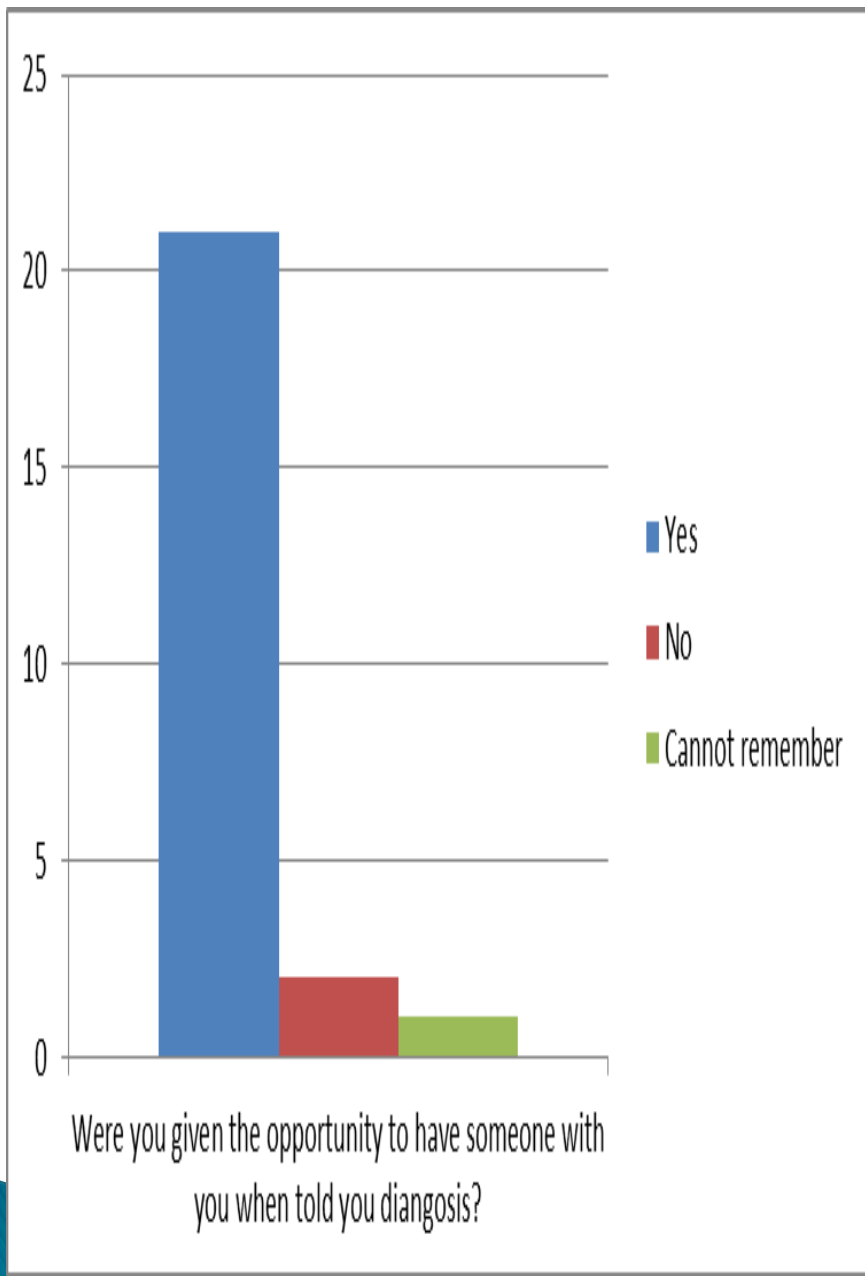
Overview

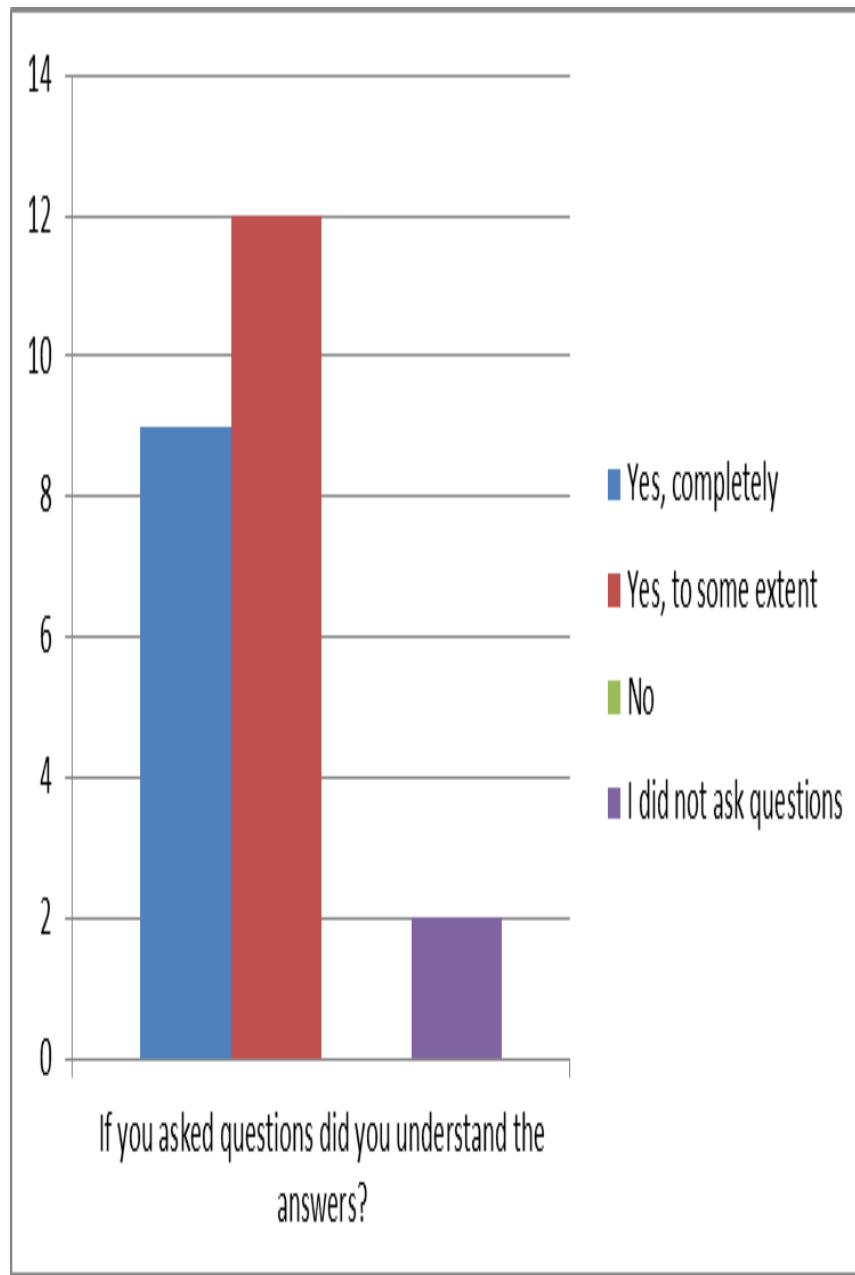
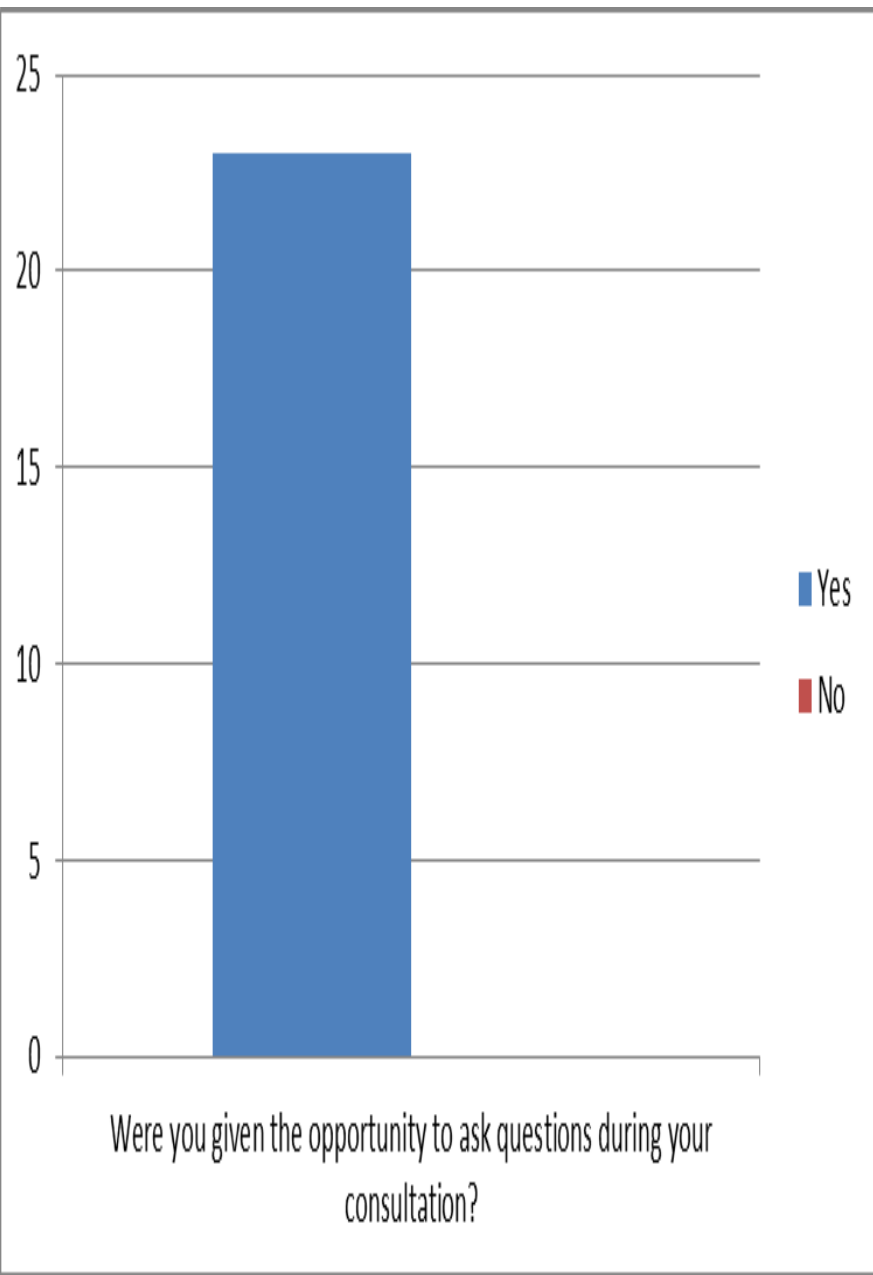
- Aim of the survey was to gauge patient opinion their experience around the time of their diagnosis and to highlight any areas of improvement
 - Particular focus was given to the diagnosis stage of the patient pathway
 - There were four sections: Communication, Privacy, Emotional support and Information
 - Returns were anonymous
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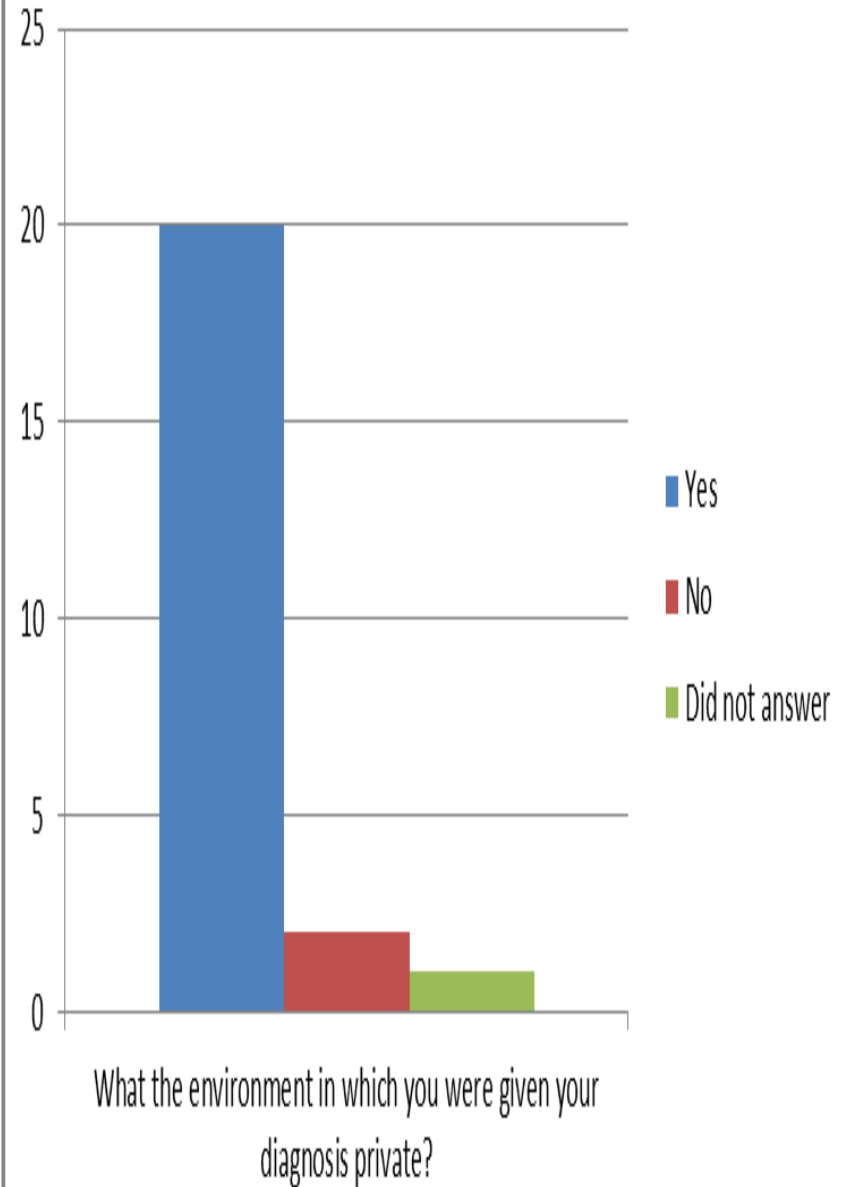
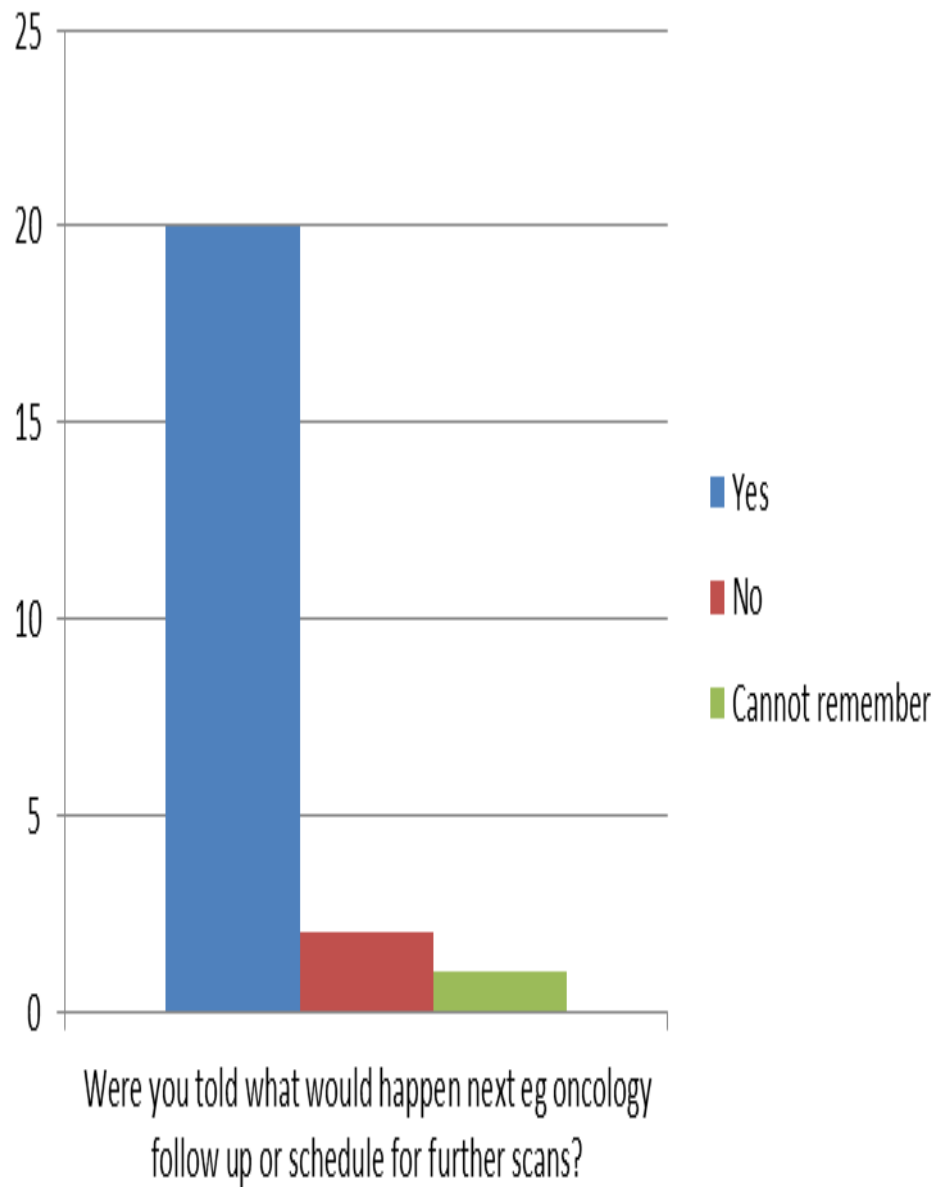
Respondent Data

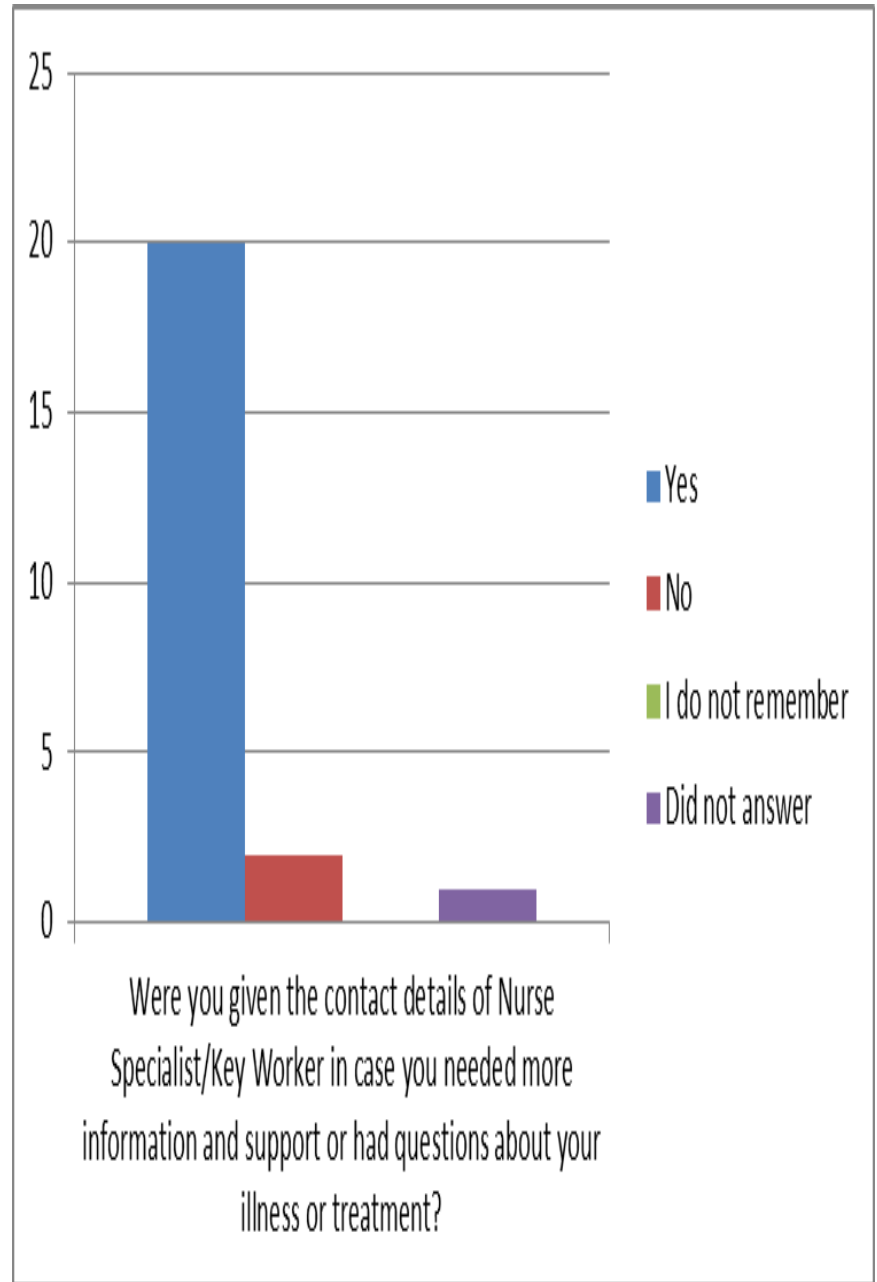
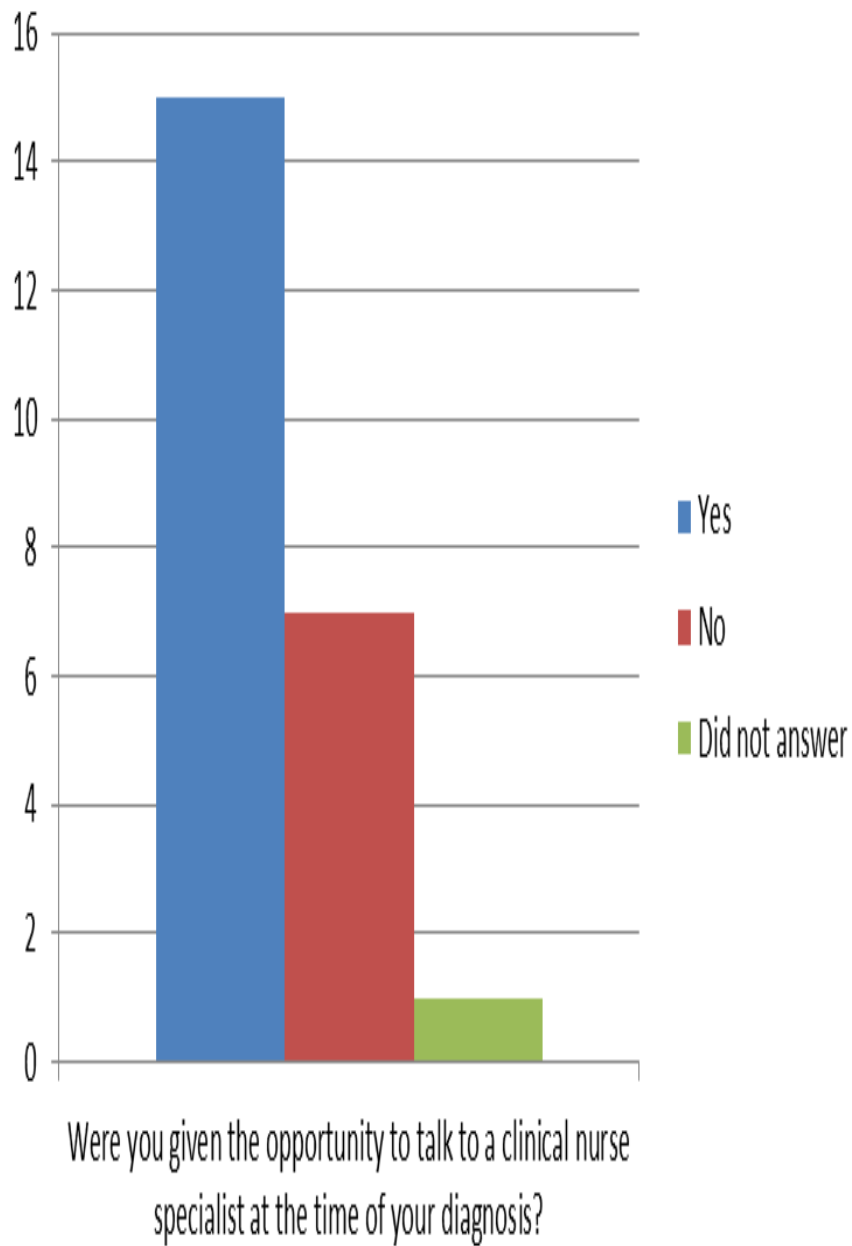
- ▶ There were 23 respondents out of 40
 - ▶ 18 were male and 5 were female
 - ▶ Age range: 24–72, 1 patient did not give age.
 - ▶ ALL patients were newly diagnosed with a primary Glioma Grade II–IV
 - ▶ Survey took place over a 5month period
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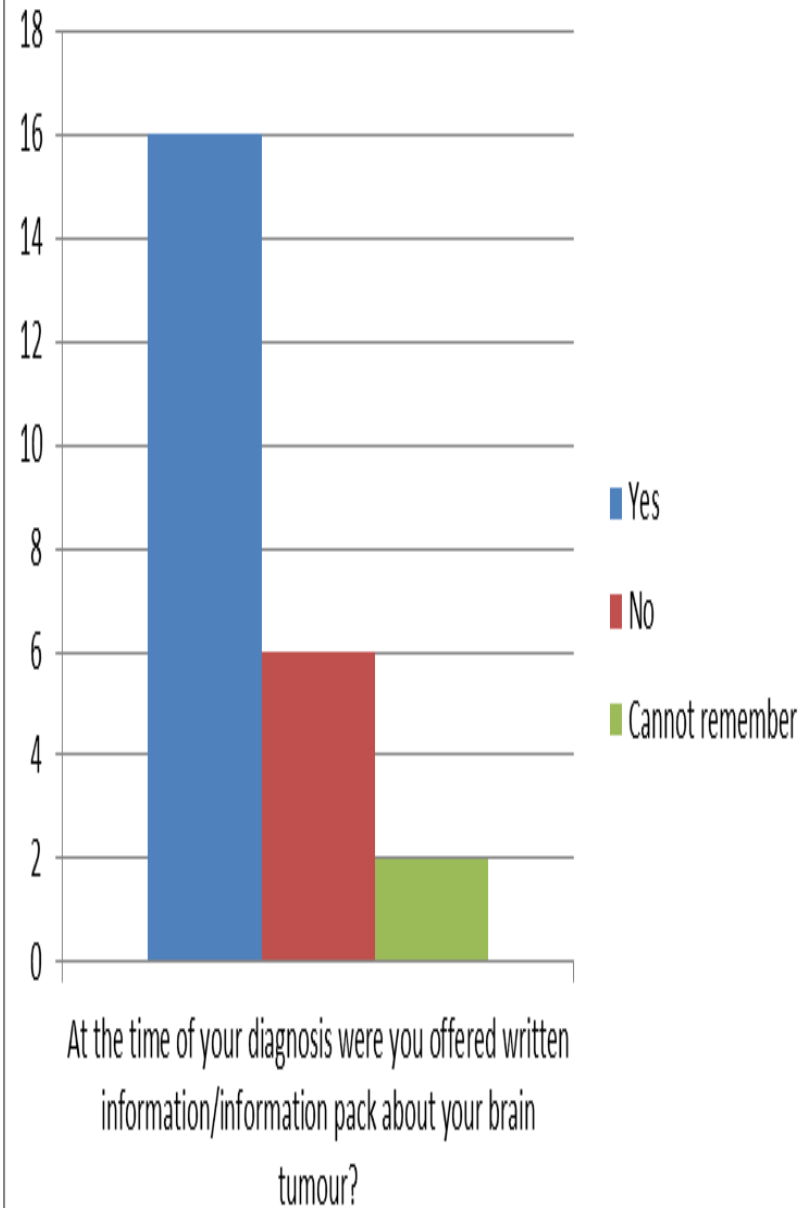
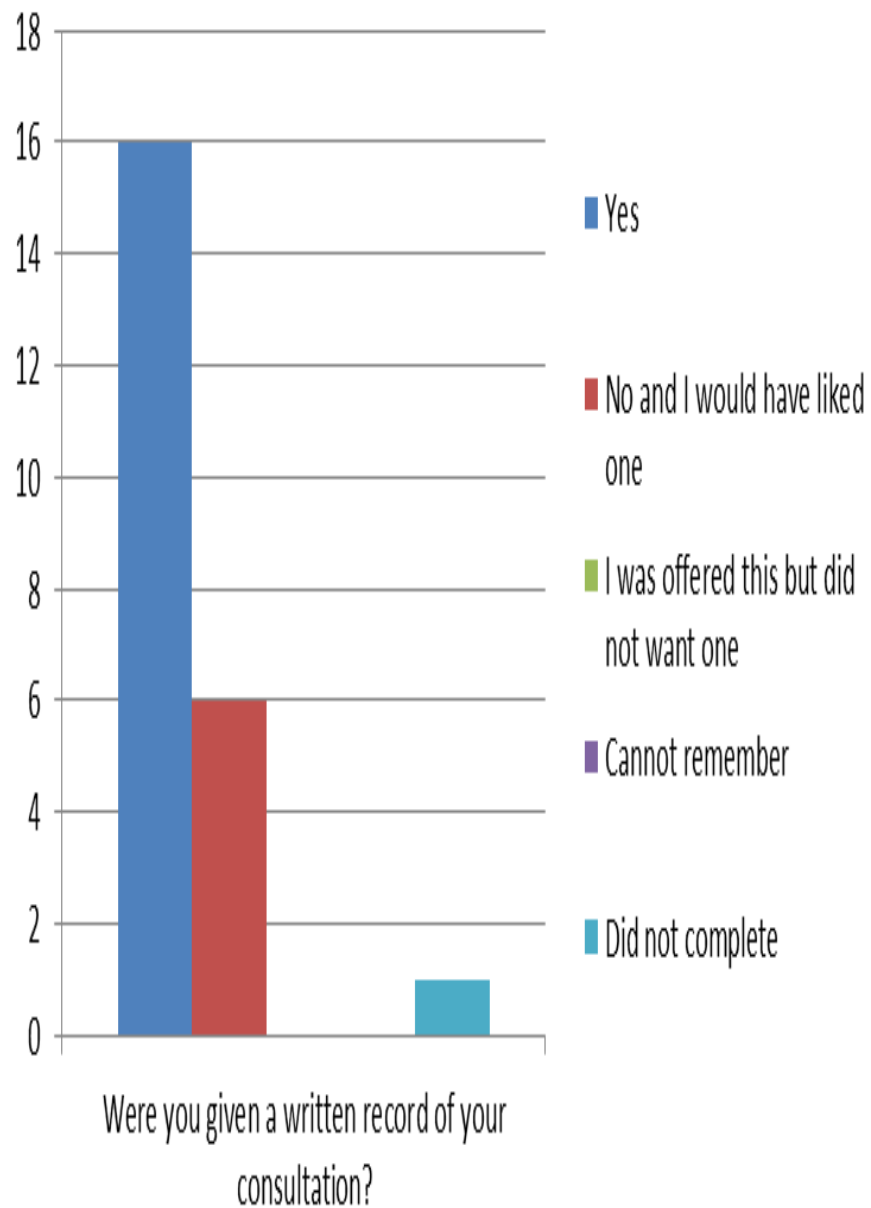


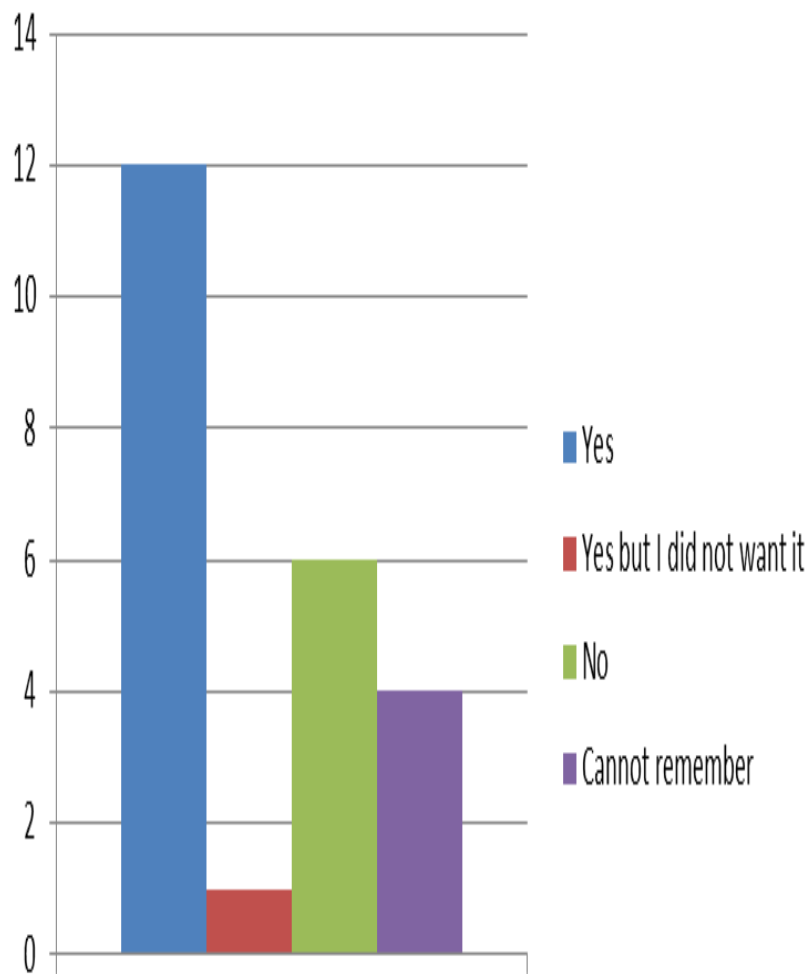




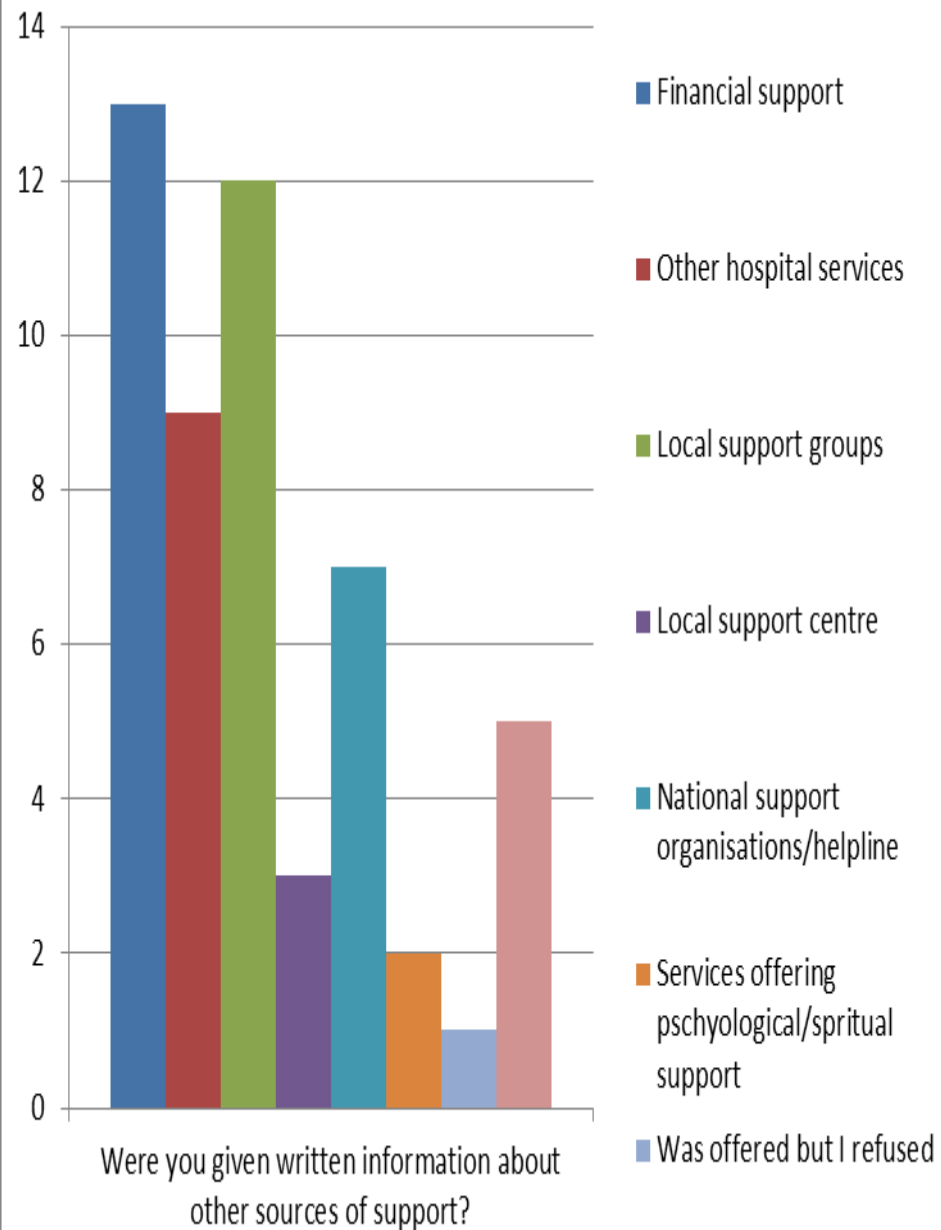




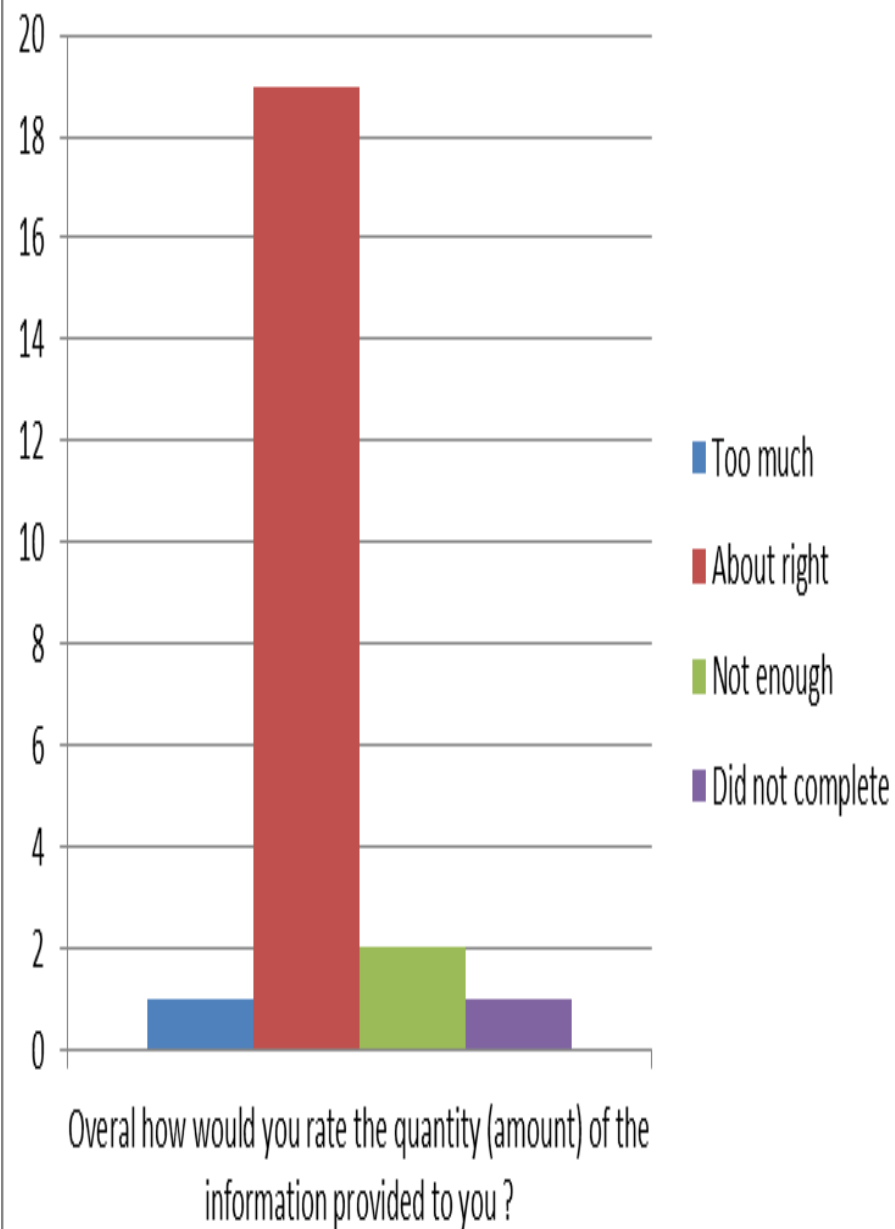
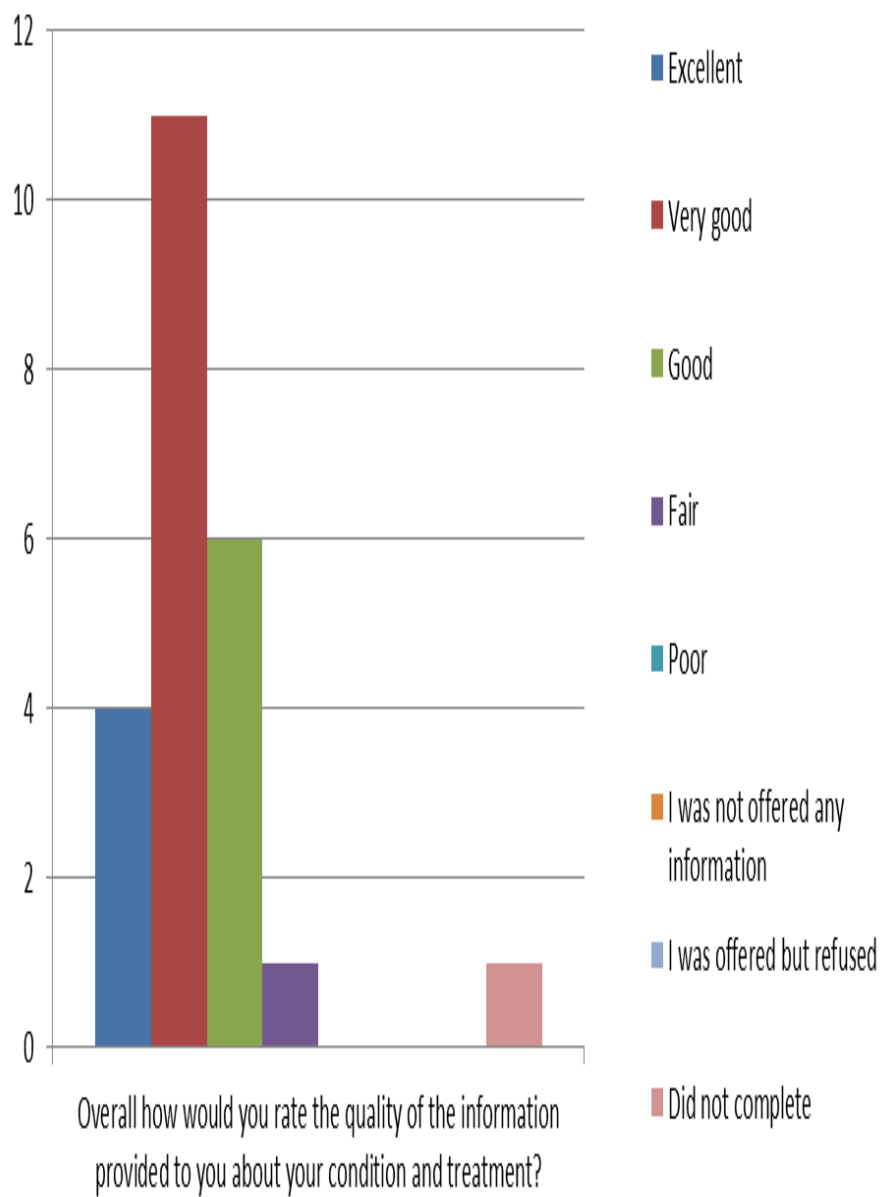


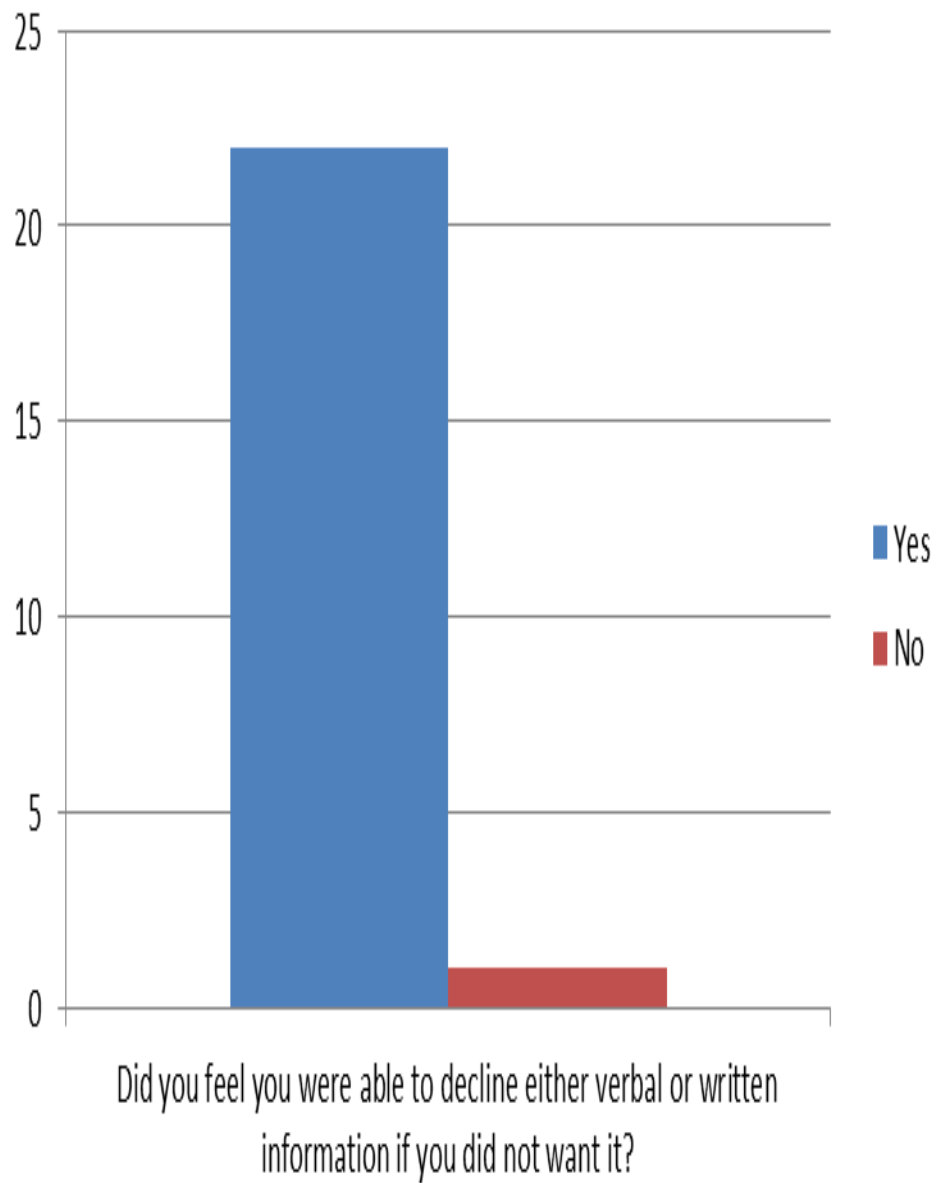


Were you offered written information about the multidisciplinary team (MDT) who would be involved in your care and what they do?

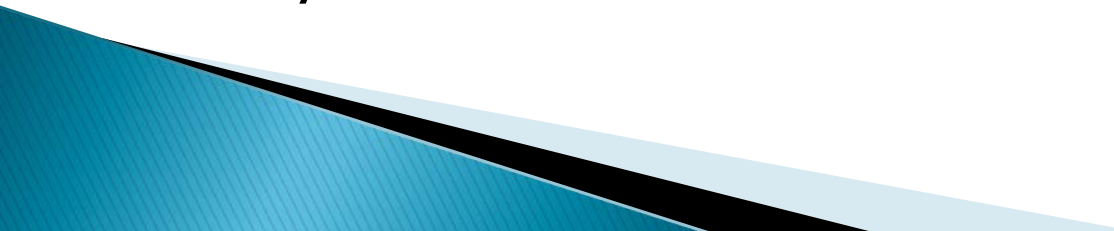


Were you given written information about other sources of support?






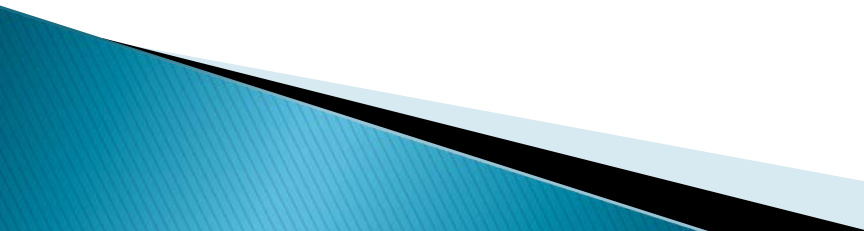
Patient Comments: Was there anything particularly good about the care you received?

- ▶ The patience and time the consultant had given and how you felt at ease and free to ask any questions
 - ▶ The Consultant was informative and approachable and the information was good, it was important for my family
 - ▶ Nursing and medical staff were very understanding, helpful and caring
 - ▶ Everything seemed to move quickly after my surgery – appointments were organised– it was as they said it would be
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Patient Comments: Was there anything that could be improved?

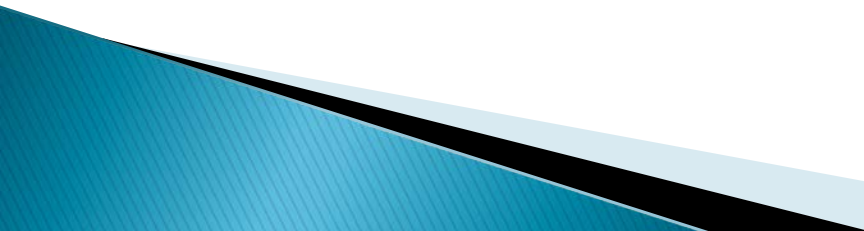
- ▶ Privacy whilst on the main ward especially when talking with consultants etc.
 - ▶ There was no privacy when talking behind a curtain
 - ▶ In this case the delivery of the diagnosis on the admission ward was too blunt and direct as it was totally unexpected
 - ▶ Yes, keeping relatives more informed after the brain surgery how it went? How much tumour was removed?
 - ▶ Feeling of isolation following completion of treatment. As I carer I would perhaps have like a clearer picture of the progression of symptoms and how to deal with them, or how to try to get on with life
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Patient Comments: Was there anything that could be improved? Cont'd

- ▶ I received my initial diagnosis in another regional hospital and I felt a lack of emotional support. Little information was given to me
 - ▶ I felt like the waiting time between my initial diagnosis and waiting to be seen by the surgeon was too long
 - ▶ Admission to Neurosurgery was a scary and daunting experience. I had no idea what to expect
 - ▶ The MDT should be more open about how they came to decisions. It should be emphasised how patients can get second opinions if they want one
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Learning from Patients and Carers

Improving service delivery

- ▶ Separate Individual consultations to discuss pathology and management plan with Consultant/Senior Doctor. Privacy is paramount
 - ▶ Written information to support appears to be helpful for patients/family members
 - ▶ Patients having the opportunity to have a family member or friend present to ask questions on their behalf
 - ▶ Patients having a plan with appointments organised– a seem-less service
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Neuro-Oncology Information Packs 2009

- ▶ Information regarding nature and grade of Tumour 2009
- ▶ Information about future treatment plan, radiotherapy and or chemotherapy 2009
- ▶ Information about medication steroids/seizures 2009
- ▶ Advice and contact numbers 2009
- ▶ Local support groups and counselling available 2009
- ▶ Additional information such as palliative care services 2009
- ▶ Individual Consultation Record 2010
- ▶ Information about lifestyle and Exercise 2011
- ▶ Information leaflet about Driving restrictions 2012
- ▶ Information leaflet regarding wound care 2013
- ▶ Neuro-Oncology MDM Leaflet 2013



Neuro-Oncology

Multi Disciplinary Team

Patient Information

Other Developments

- ▶ Pre -op assessments and pre-op visits/pre treatment visits to Cancer Centre particularly for young patients/teenagers
 - ▶ The appointment of adolescent CNS in Cancer Centre
 - ▶ Looking towards the future development of a post MDM clinic to assess patients, convey clinical information
 - ▶ Continuing to support professional colleagues across NI
 - ▶ Furthers surveys to gauge neuro-oncology patients experience of going through radiotherapy/chemotherapy and follow-up
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