



Understanding the Patient's Experience of Rare and Less Common Cancers

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Quality Health

The National Cancer Patient Experience Survey Programme



- ▶ One of the largest cancer surveys in the world
- ▶ Running since 2010
- ▶ Questionnaires sent to all patients being treated for cancer between September and November each year
- ▶ In 2014: 153 NHS Trusts, 109,760 patients
- ▶ Overall response rate: 64% (70,141 patients)
- ▶ Confidence interval +/- 0.3% at 95%
- ▶ Being replicated in Australia, Iceland, Ireland, Isle of Man, New Zealand, Qatar, Scotland, Taiwan, Wales

The big picture



- ▶ Overall, cancer patient experience is very positive: on half of the questions, scores are 80%+
- ▶ On comparable questions, cancer patients are more positive than others
- ▶ Significant improvements over time at national level: on over two thirds of questions
- ▶ Most individual Trusts have improved too – some radically
- ▶ But there are big differences between Trusts, e.g. on how easy it is to contact a Clinical Nurse Specialist (58% to 92%)
- ▶ And some scores are declining nationally, e.g. on the transition between primary and acute care

Improvements 2010-14

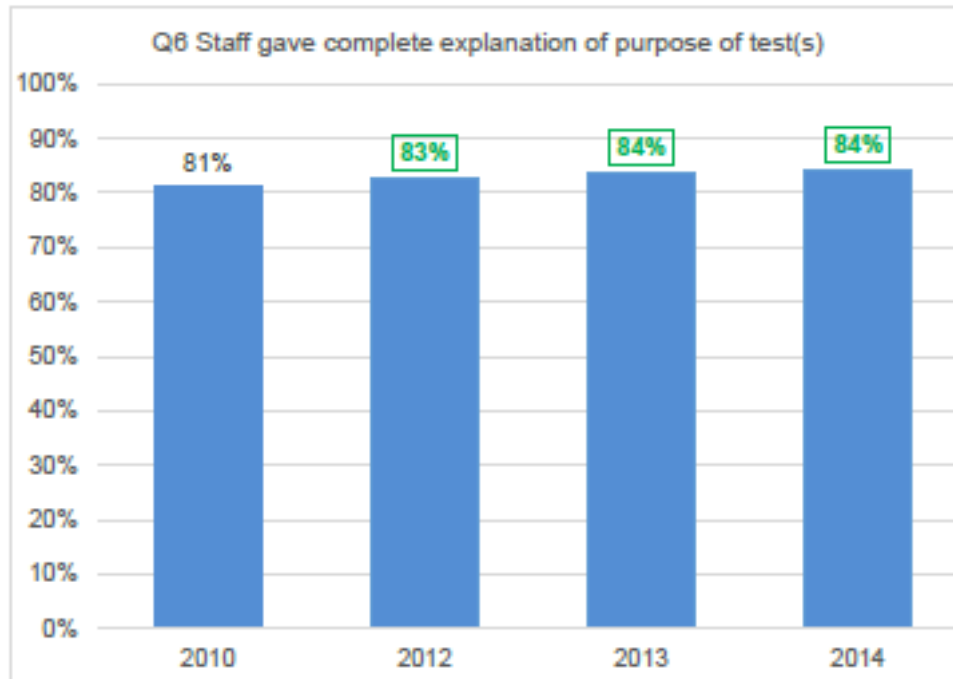


Chart 25 Explained purpose of tests

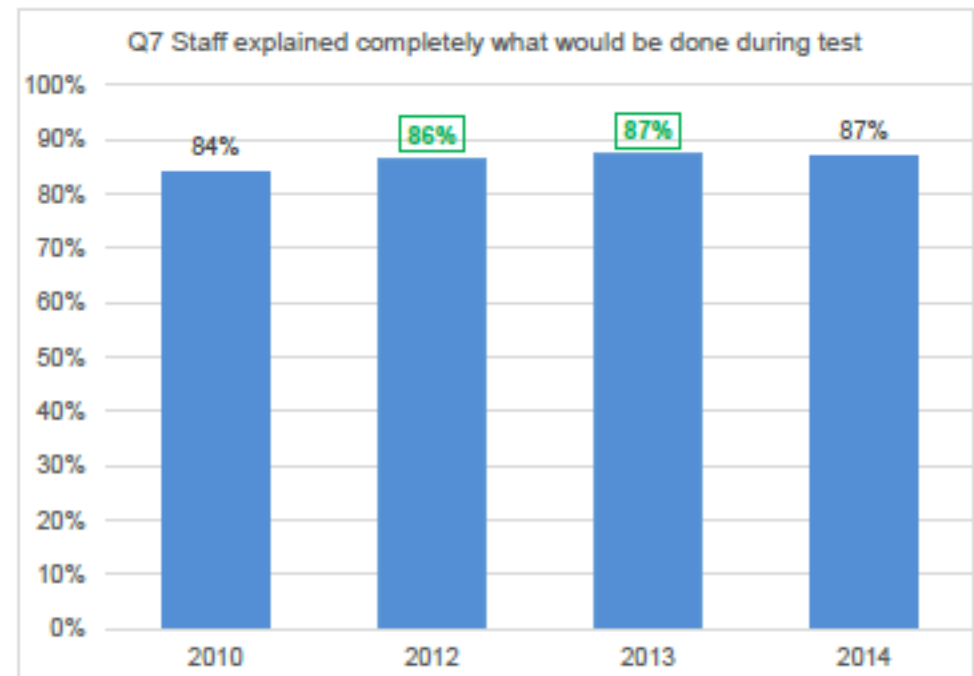


Chart 26 Explained what be done during tests

Improvements 2010-14

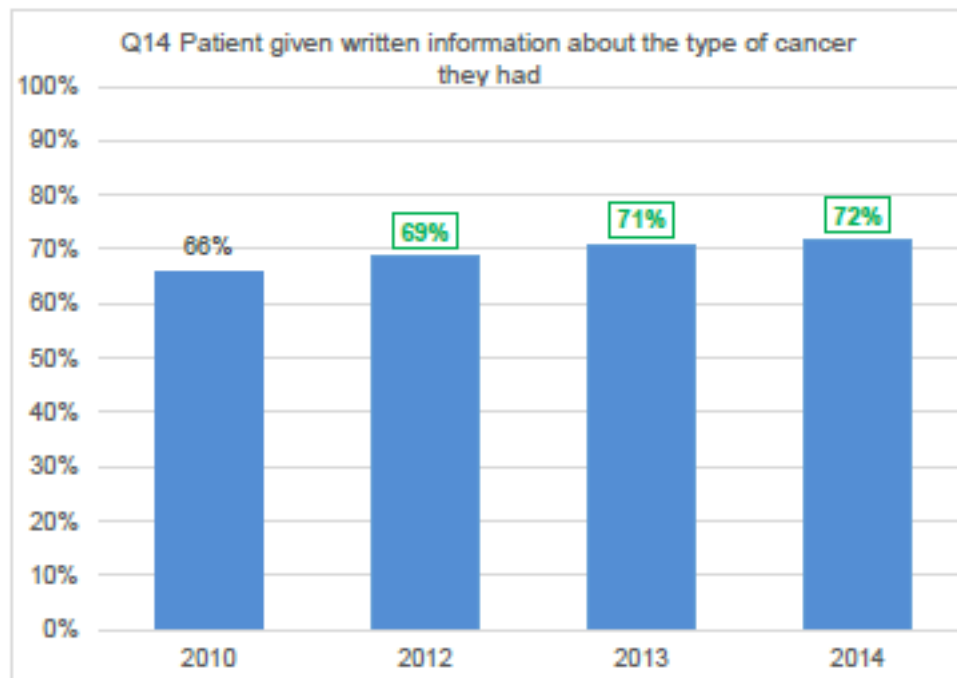


Chart 37 Given written Information about type of cancer

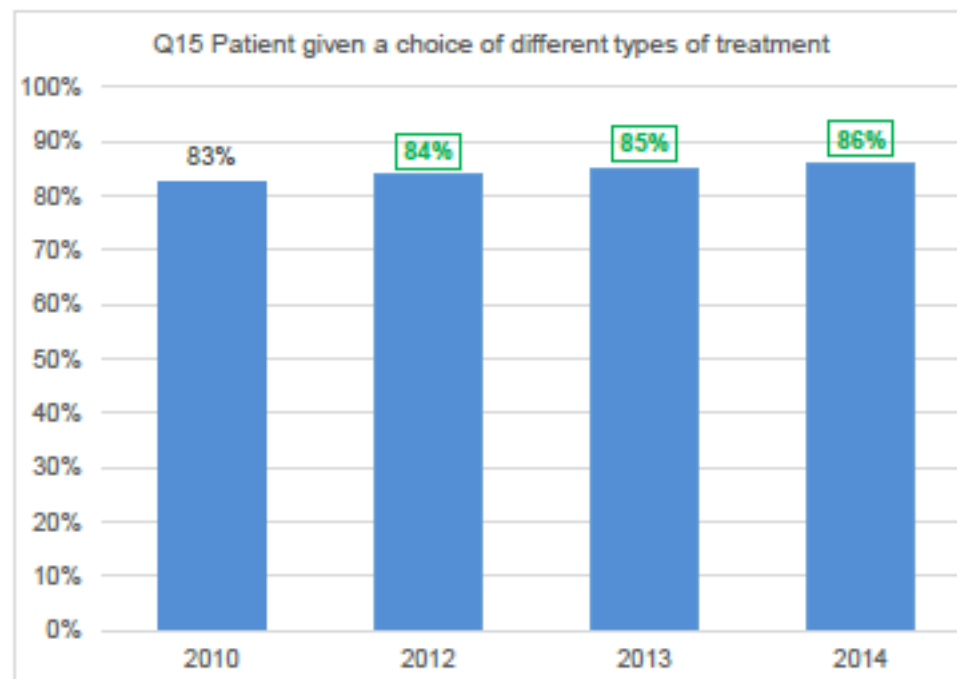


Chart 39 Given choice of treatment

Improvements 2010-14

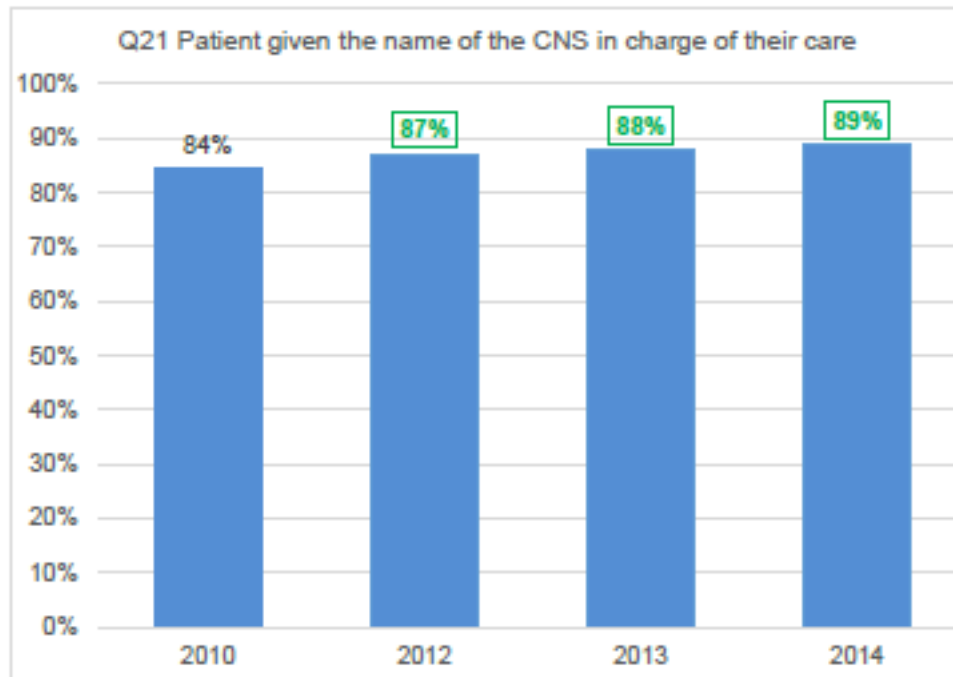


Chart 50 Q21 Given name of CNS

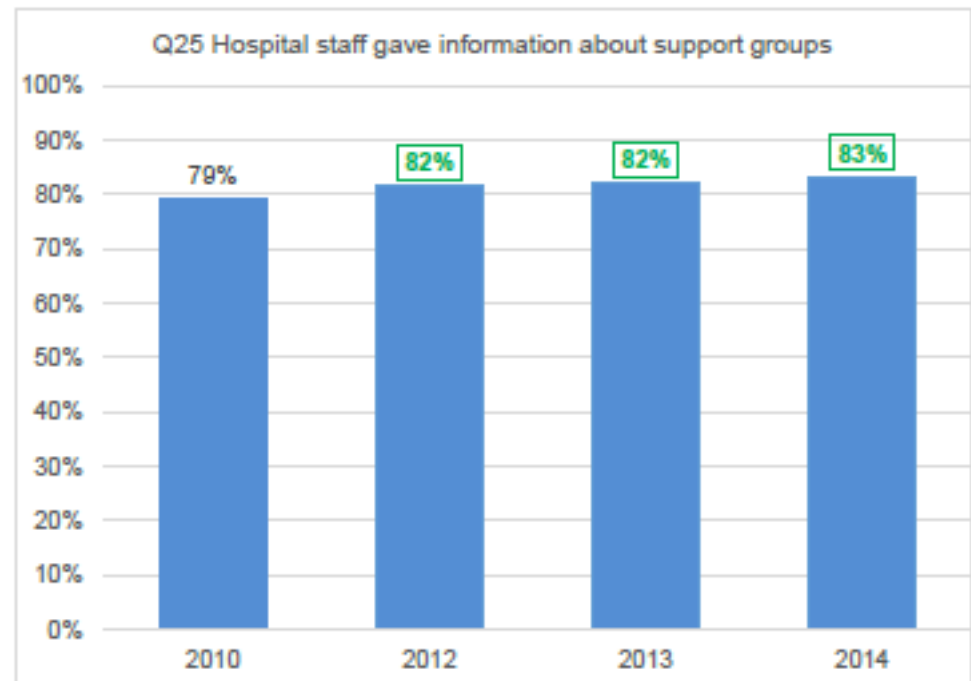


Chart 56 Q25 Given Information about support groups

Improvements 2010-14

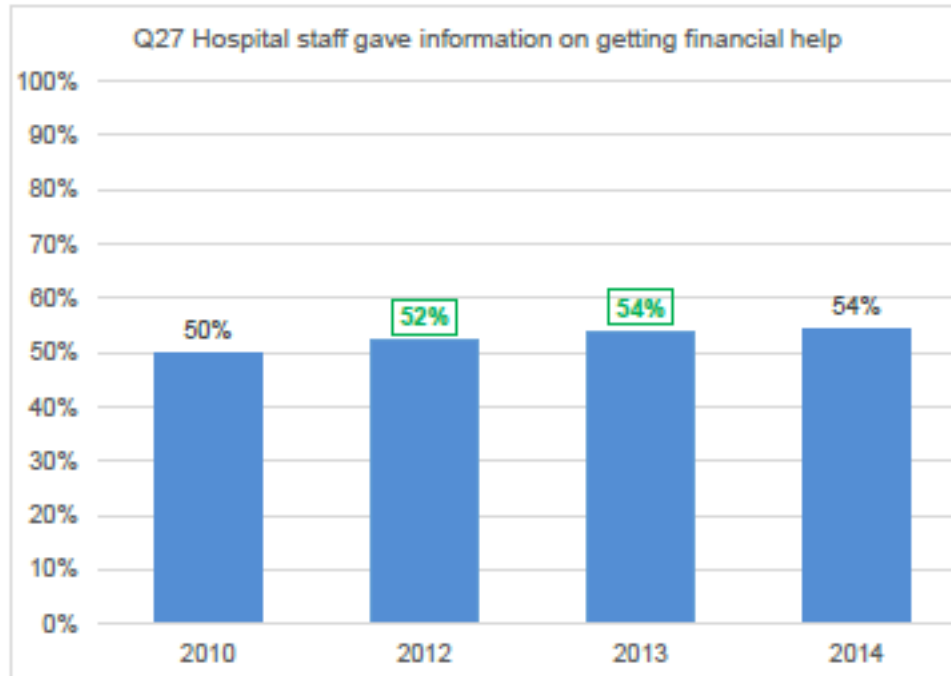


Chart 60 Q27 Given Information on financial help

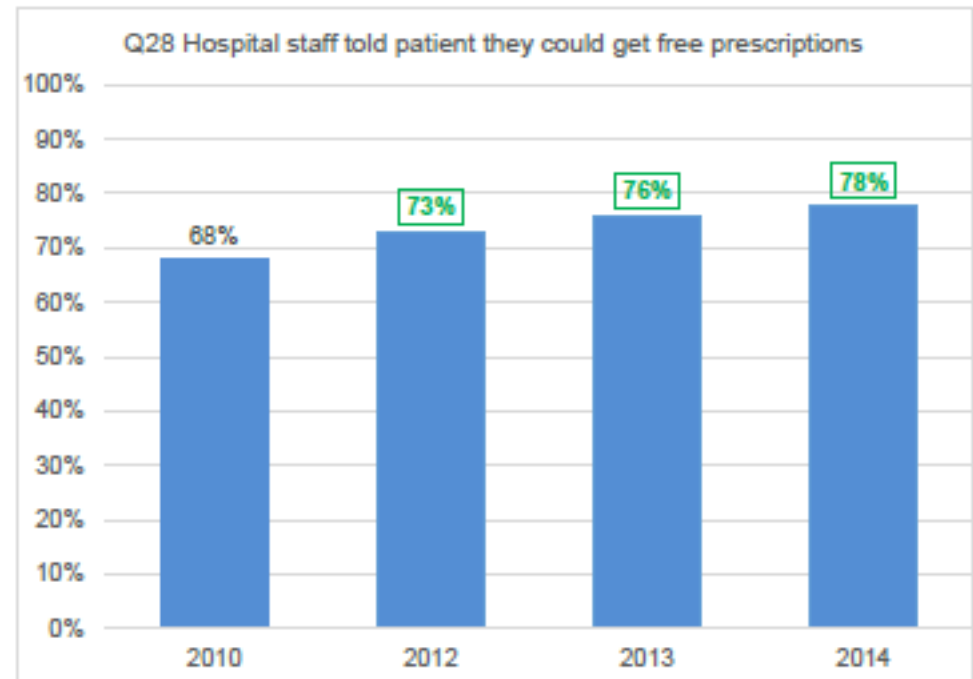


Chart 62 Told could get free prescriptions

Improvements 2010-14

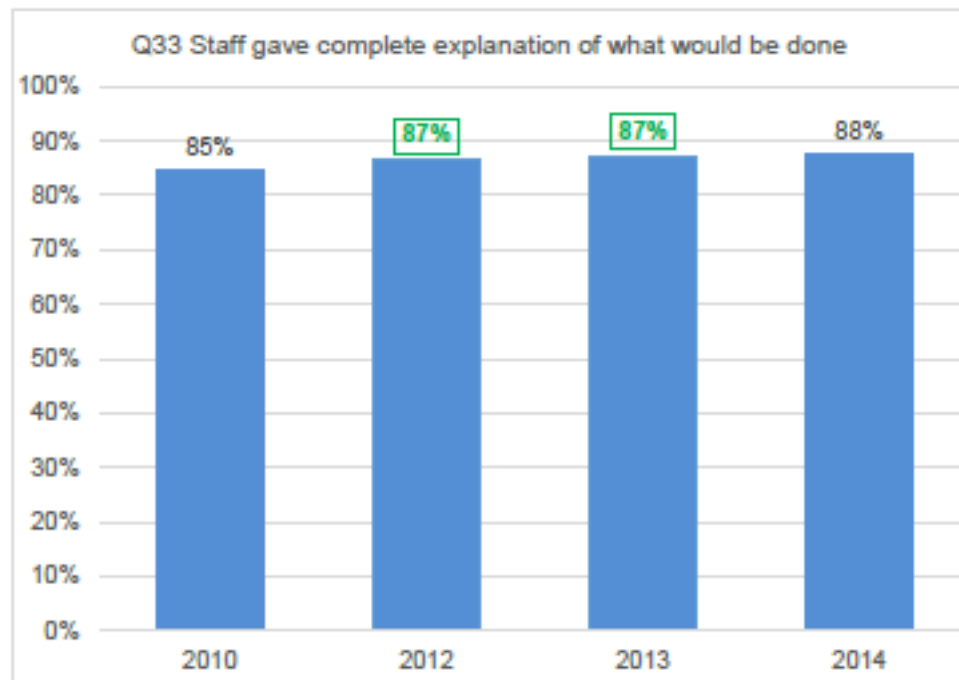


Chart 72 Given Information on operation

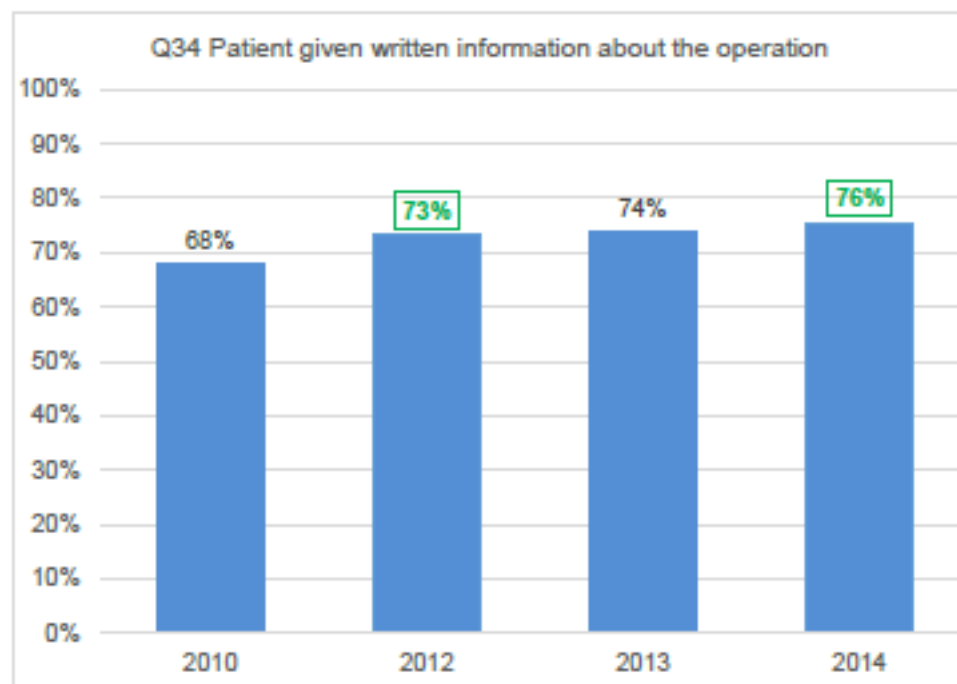


Chart 73 Given written Information about operation

Improvements 2010-14

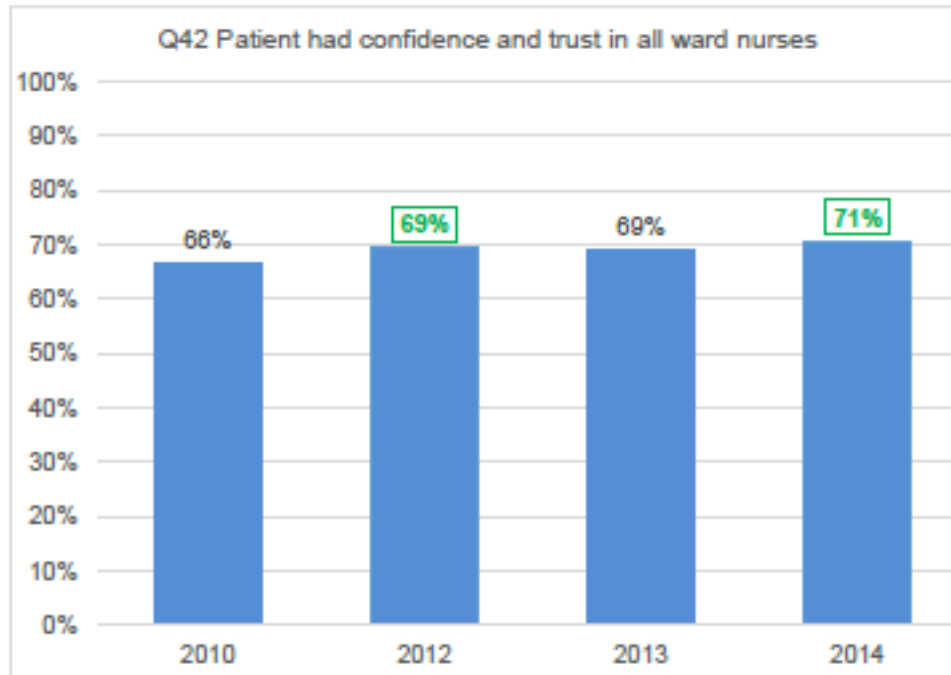


Chart 85 Had confidence and trust in ward nurses

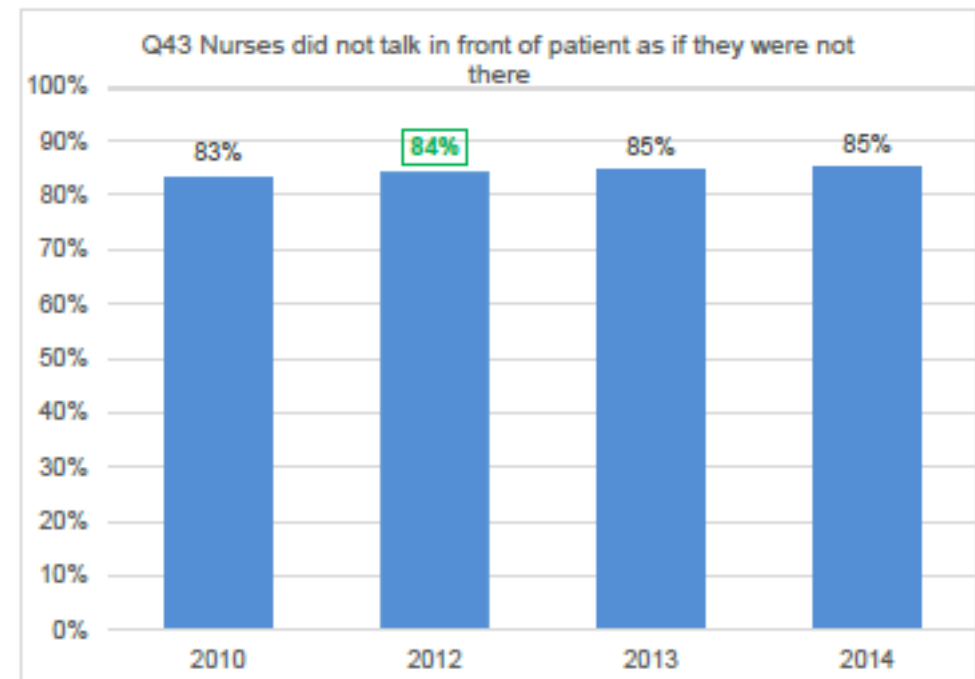


Chart 87 Nurses did not talk in front of patients as if not there

Improvements 2010-14

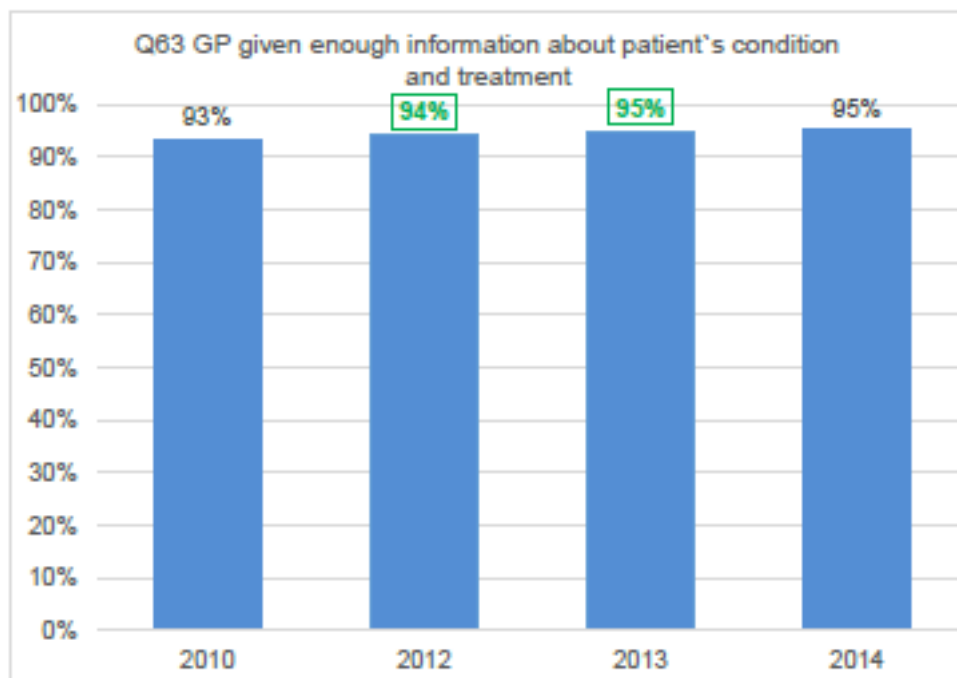


Chart 114 GP given enough information about condition



Chart 117 Staff worked well together

Behind the data



- ▶ Key Driver Analysis shows that the single most important factor is having a Clinical Nurse Specialist: it drives positive responses in all other questions in the survey
- ▶ Patients diagnosed more than five years ago tend to be less positive than those diagnosed in the last year
- ▶ Patients entering treatment through ED are much less likely to be positive than those entering through other routes
- ▶ Patients with a recurrence of cancer, and those who have had ineffective treatment, give poorer scores

Patients are less positive if...



- ▶ They live in London
- ▶ They live in more deprived areas
- ▶ They are women (on most questions)
- ▶ They are under 25; or over 75 (on some questions)
- ▶ They are from ethnic minorities
- ▶ They are not heterosexual
- ▶ They have a mental health or long term condition

These findings have applied to every iteration of the survey since 2010

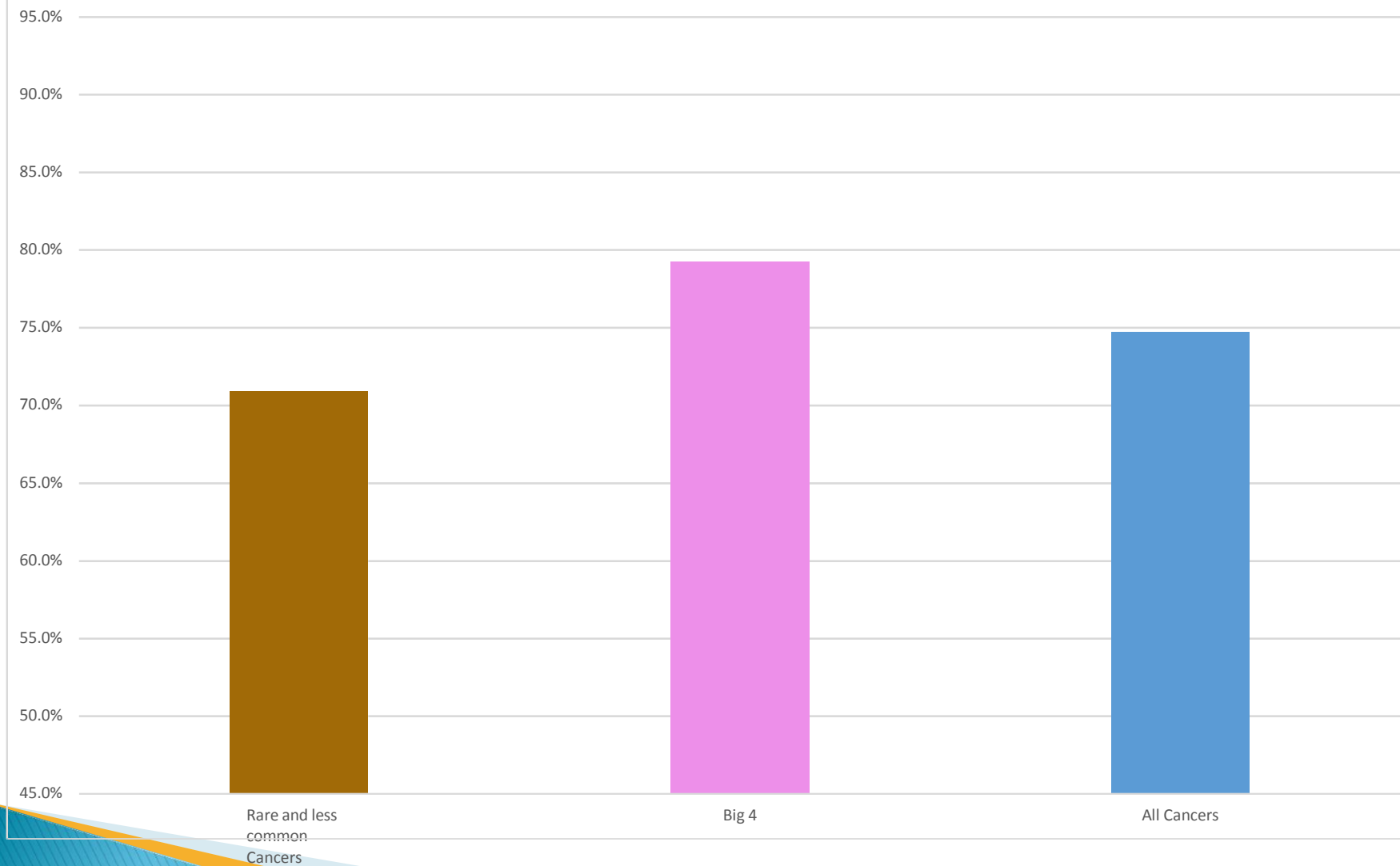
Rare and less common cancers



- ▶ The other significant finding is that patients with rare and less common cancers report a less positive experience on virtually every question than those with one of the Big 4 (breast, colorectal/lower gastrointestinal, lung and prostate)
- ▶ Quality Health has been working with Cancer52 to examine some of the most significant differences
- ▶ Reviewed all 70 questions within the NCPES 2014 and split the data into three – all cancers, ‘big 4’ and ‘rare and less common cancers
- ▶ Present here selection of 20 questions that identify some of the bigger gaps in findings

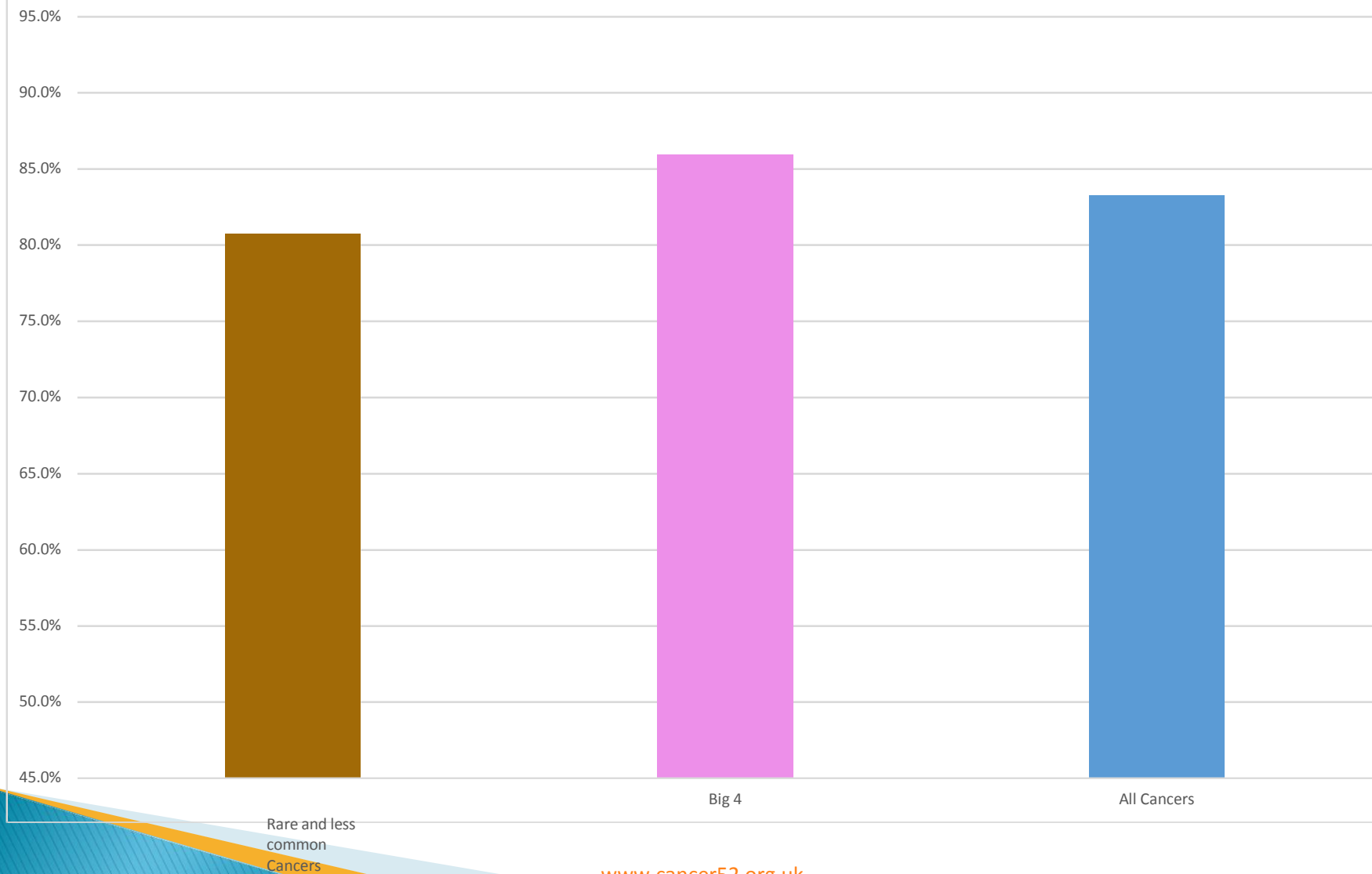


Q1 Saw GP once/twice before being told had to go to hospital



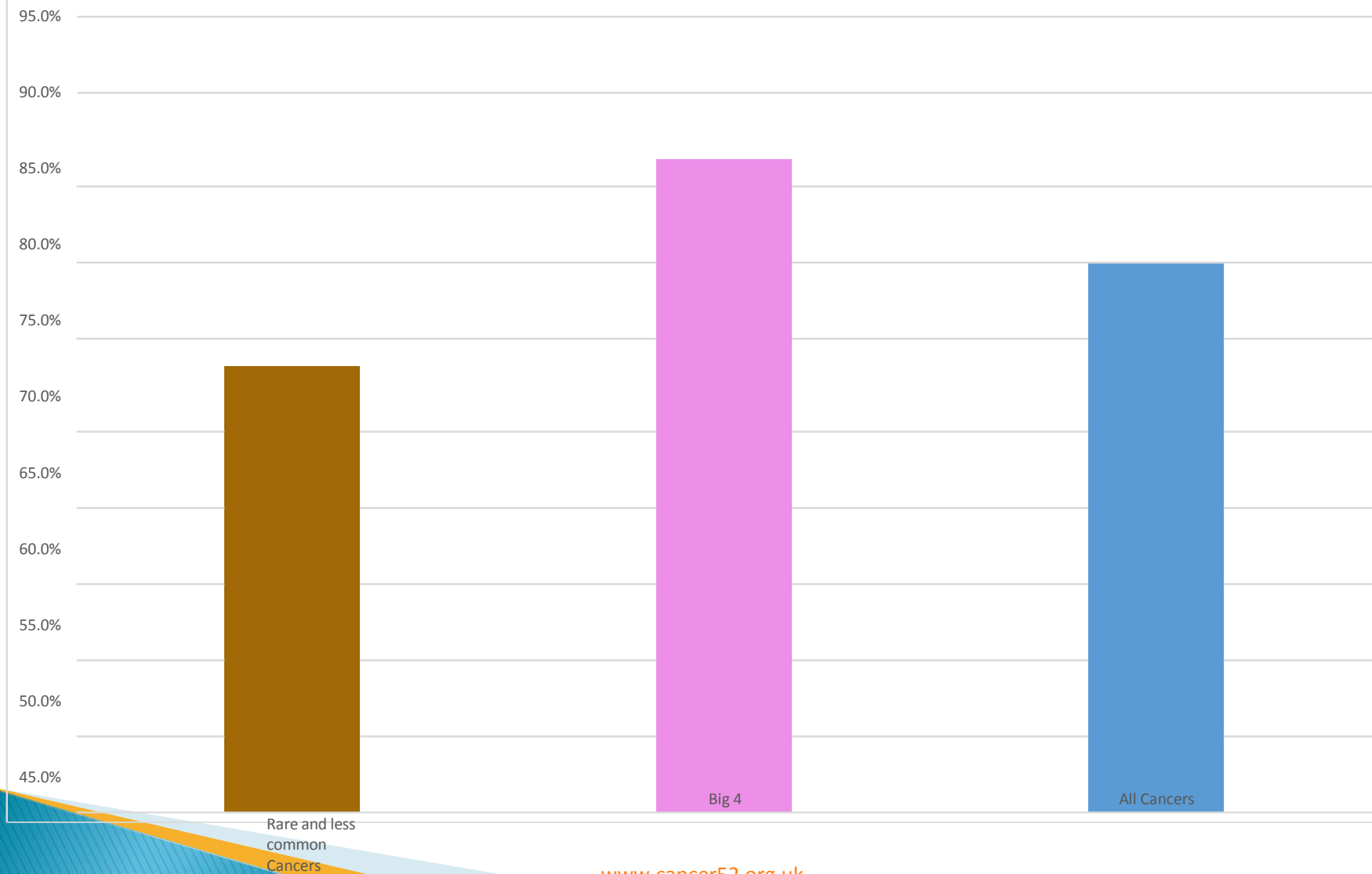


Q2 Patient thought they were seen as soon as necessary



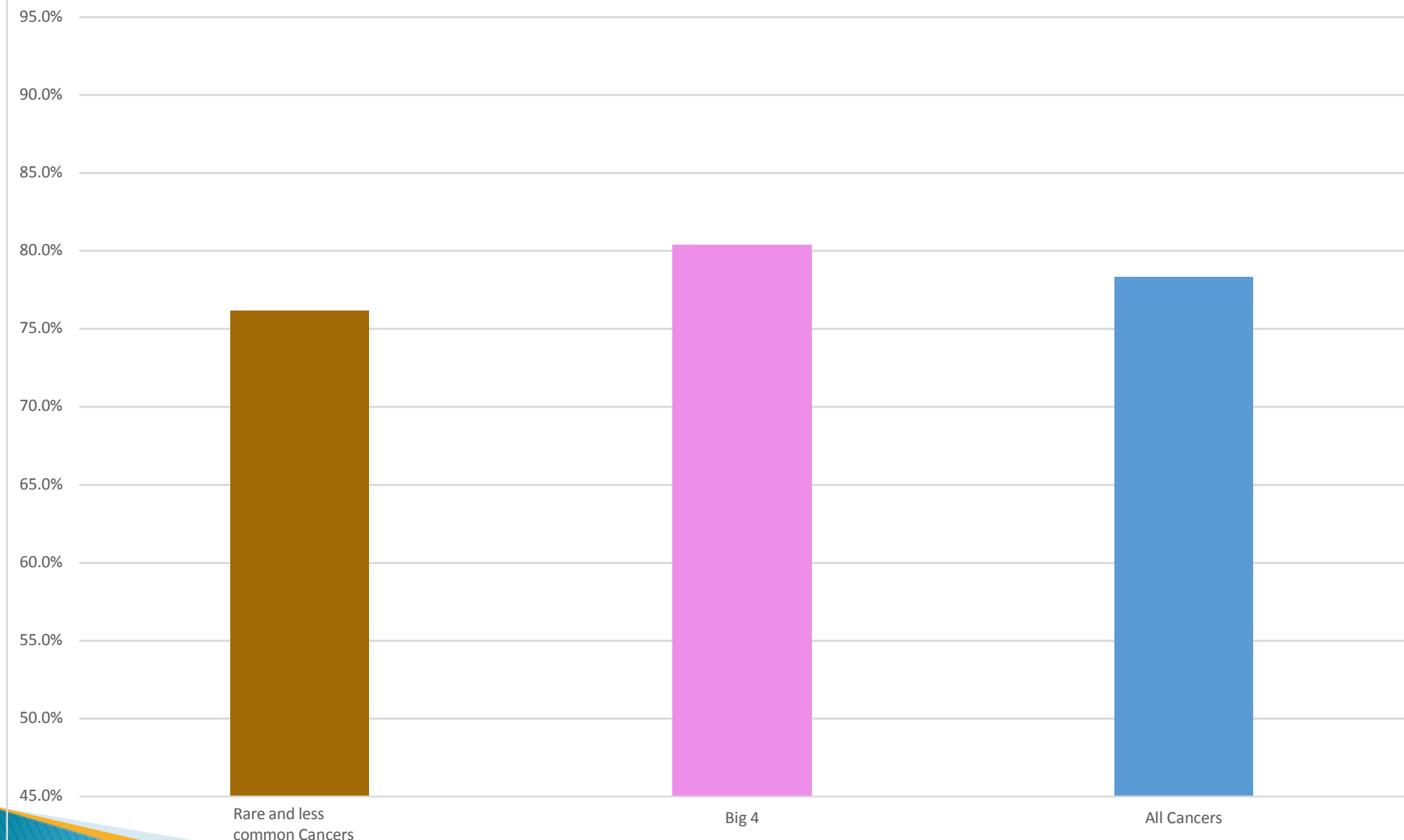


Q4 Patient's health got better or remained about the same while waiting



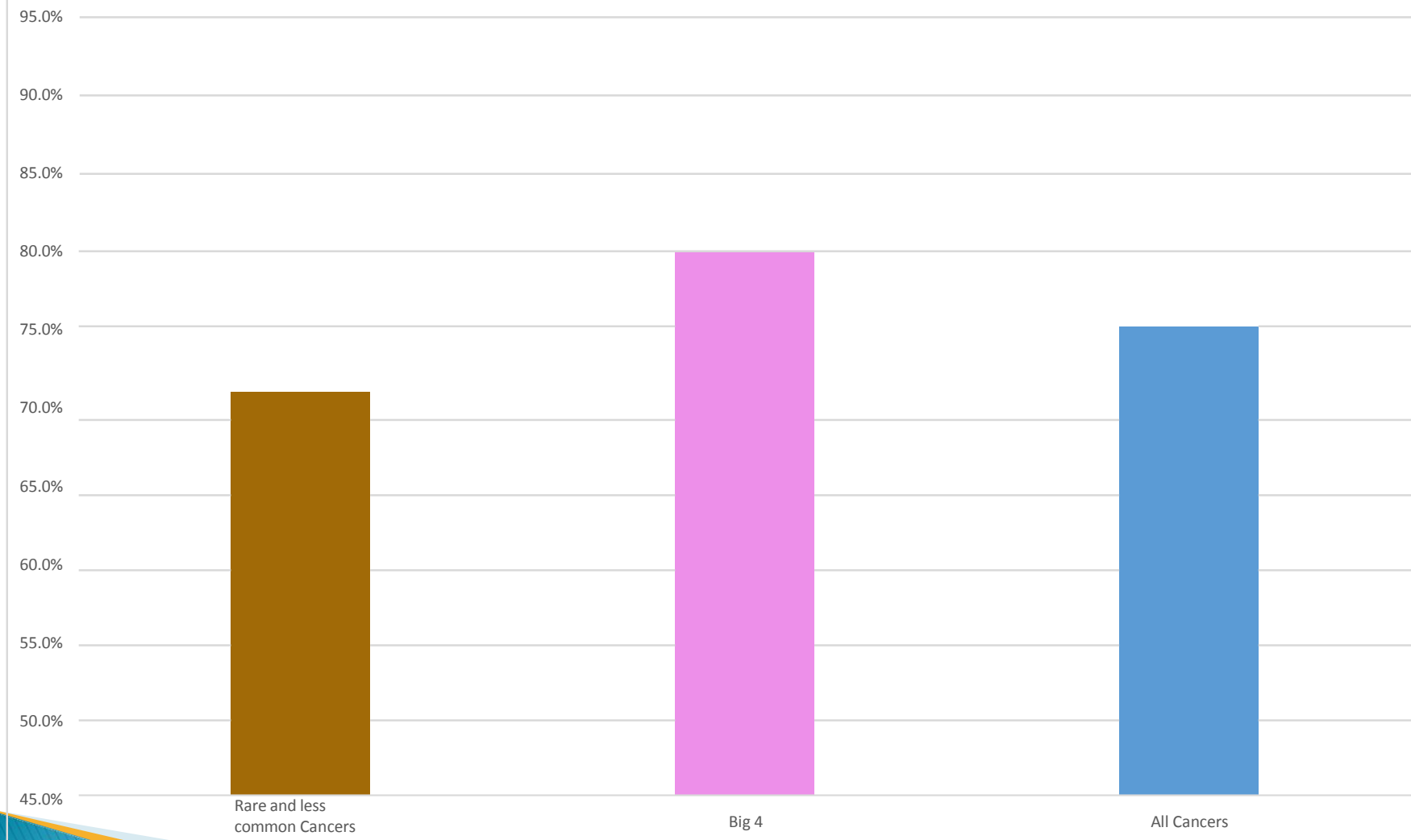


Q9 Given complete explanation of test results in understandable way



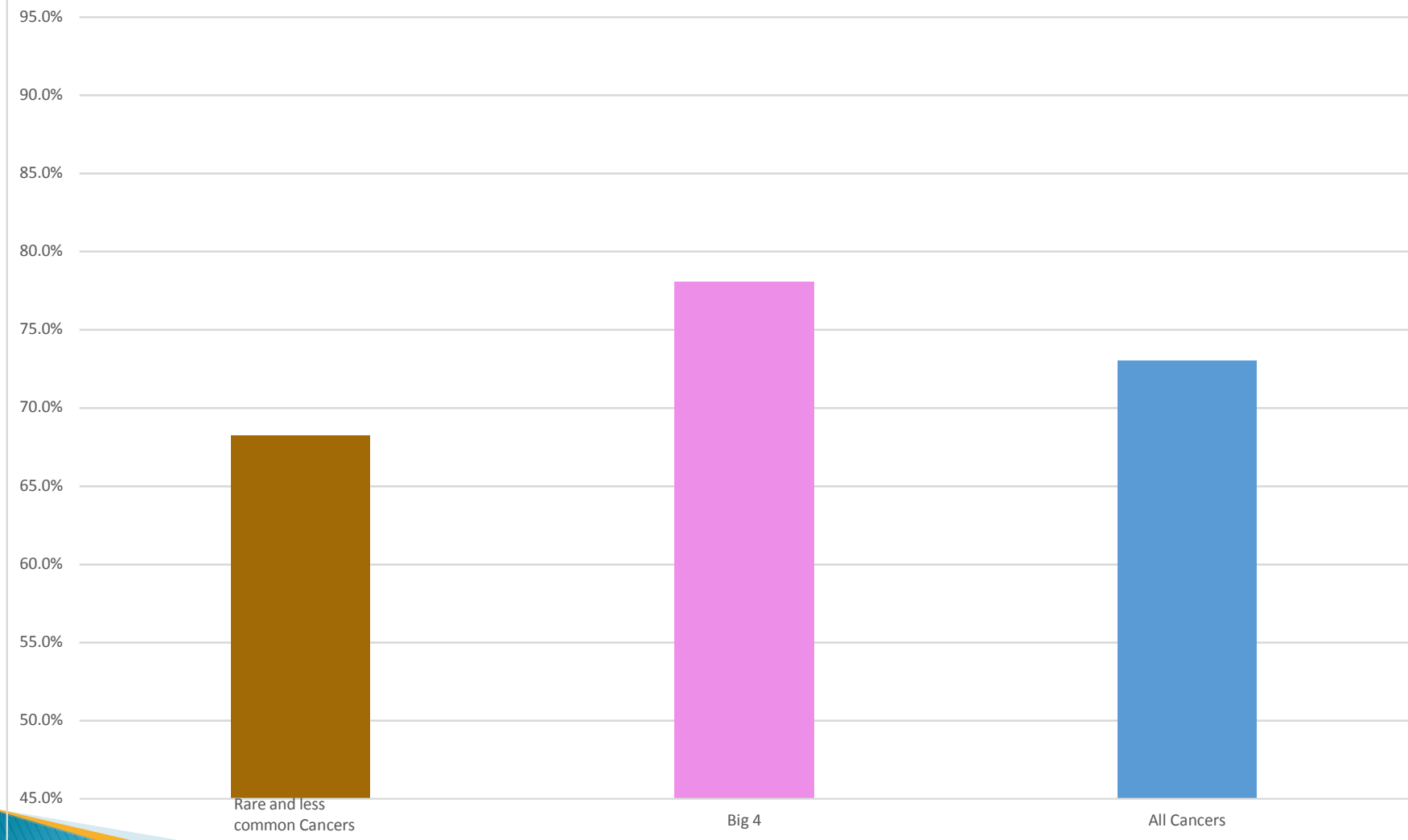


Q11 Patient told they could bring a friend when first told they had cancer



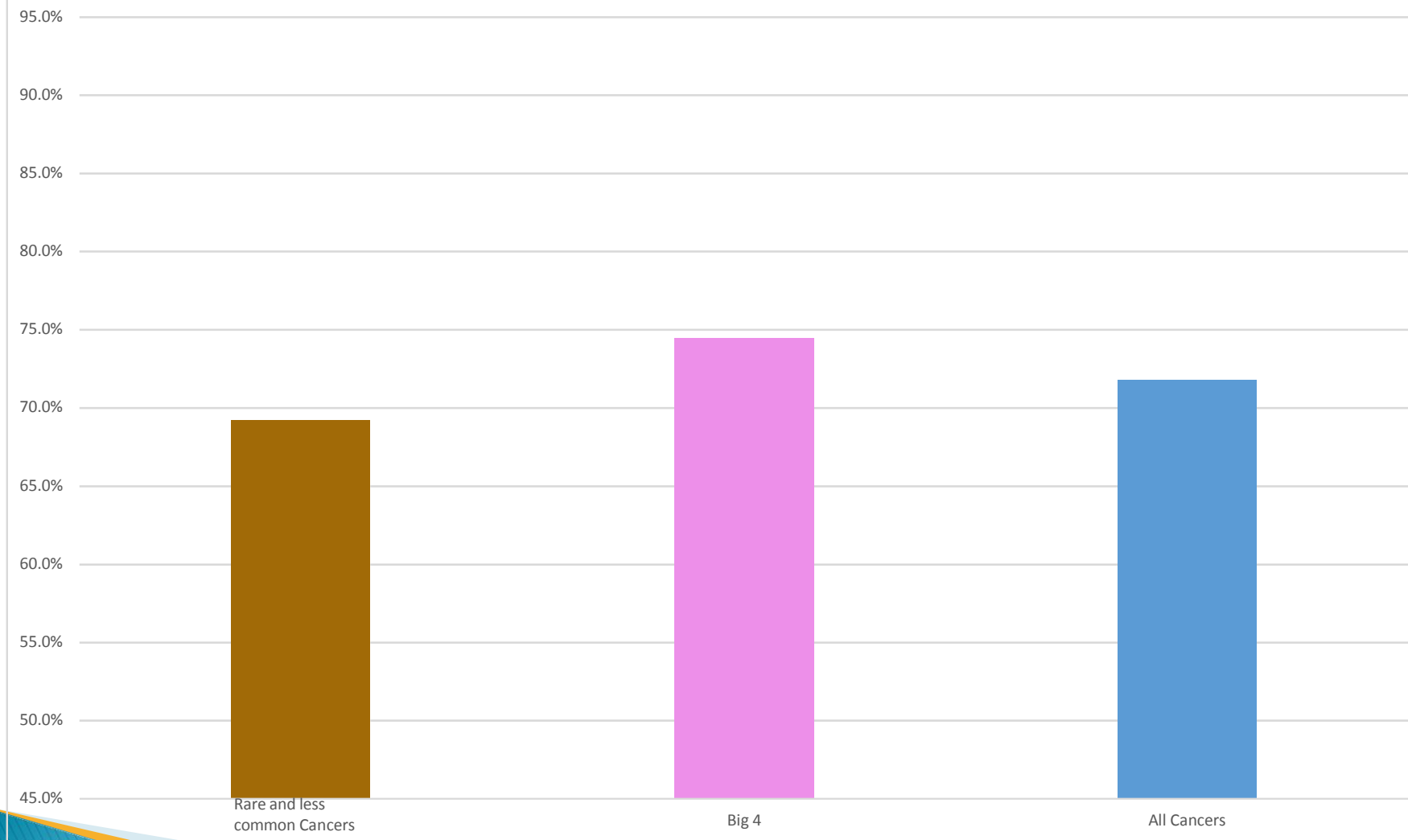


Q13 Patient completely understood the explanation of what was wrong



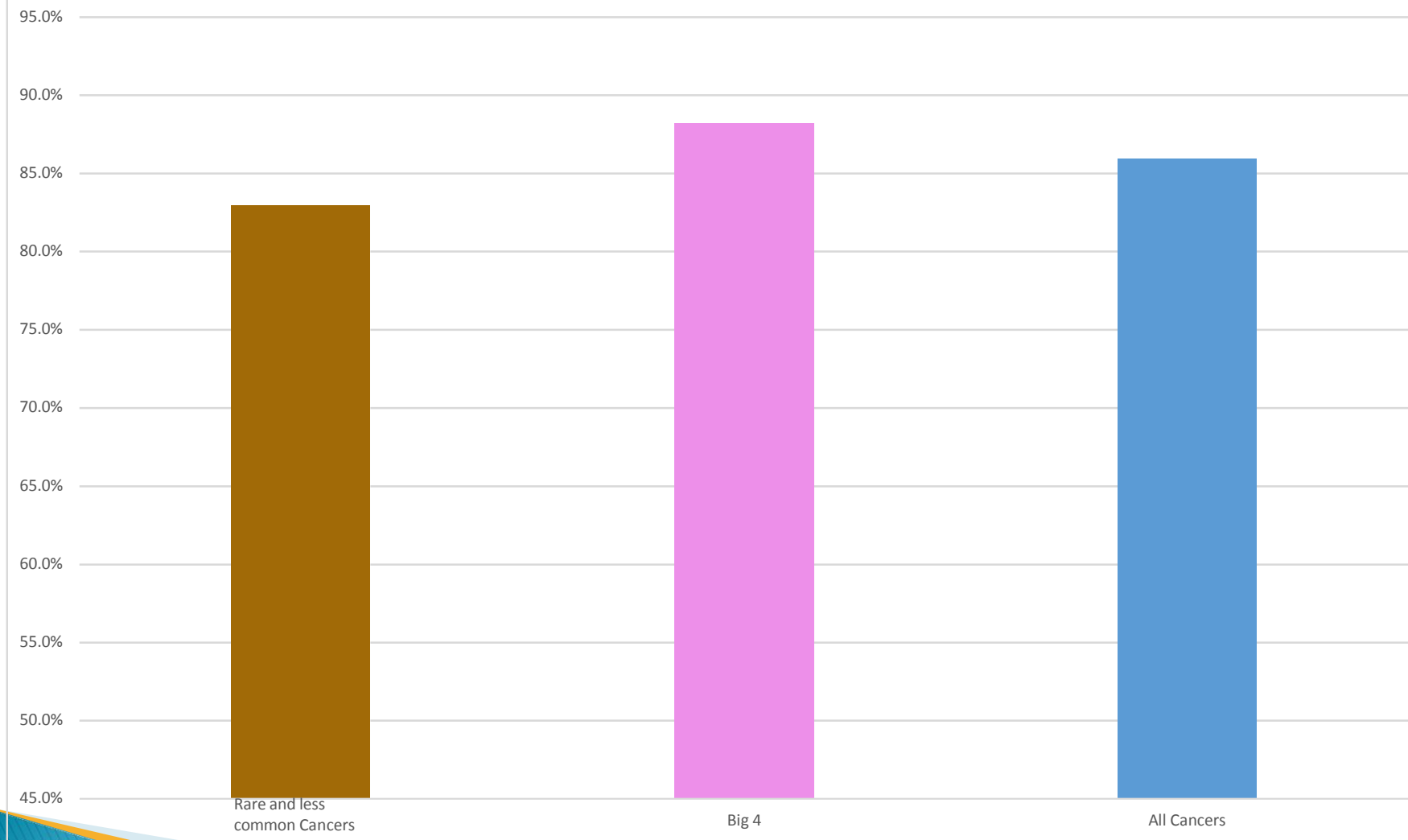


Q14 Patient given written information about the type of cancer they had



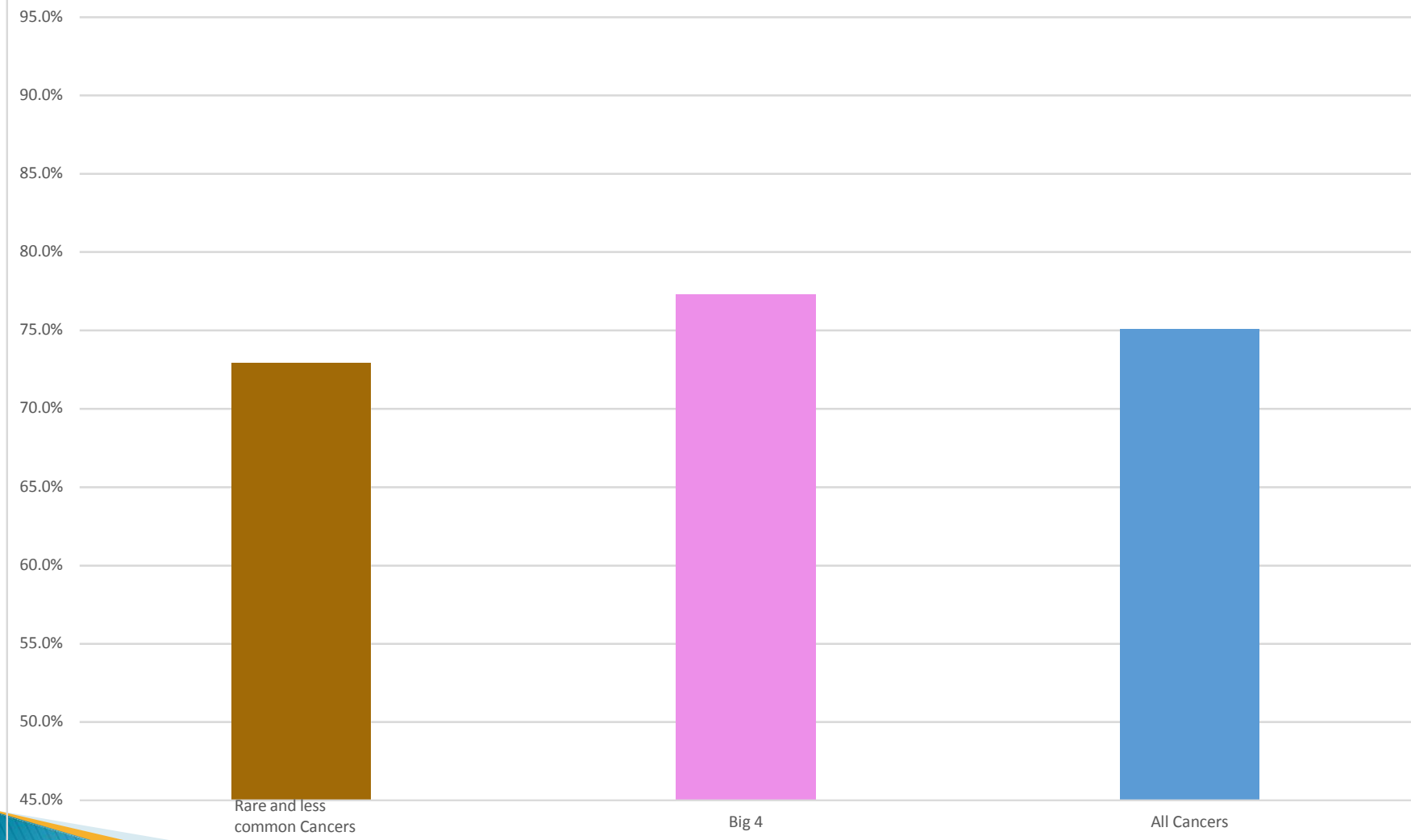


Q15 Patient given a choice of different types of treatment



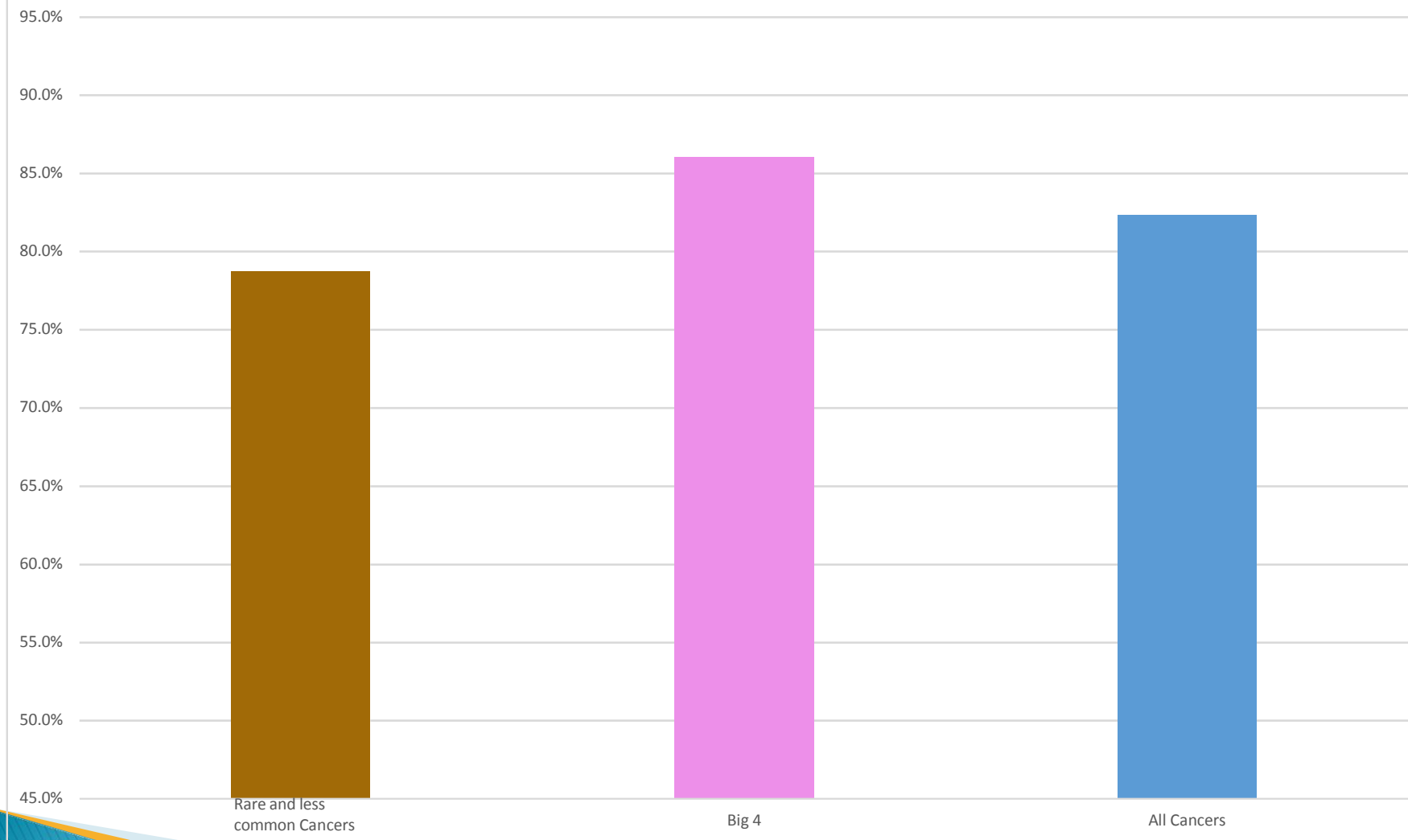


Q17 Possible side effects explained in an understandable way



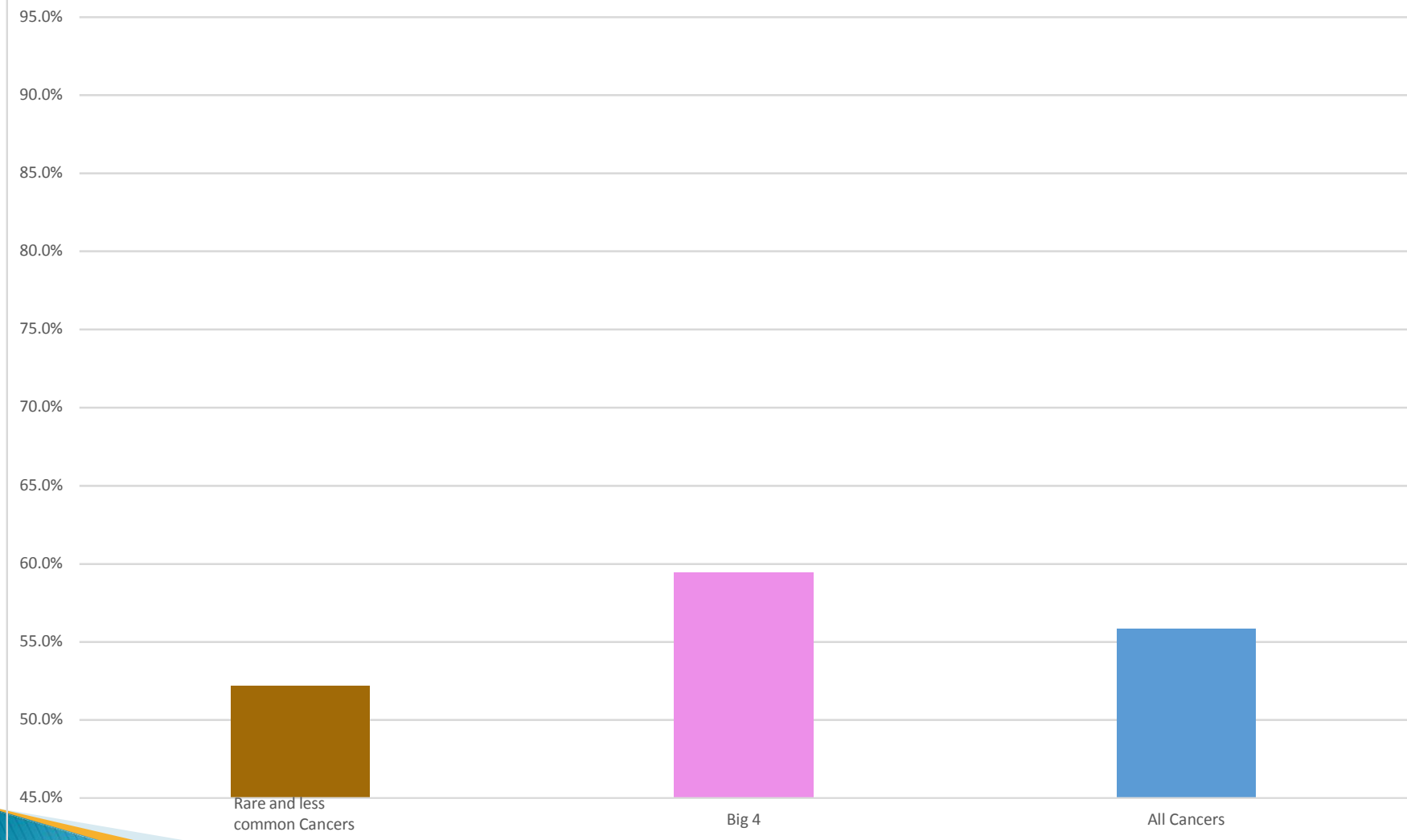


Q18 Patient given written information about side effects



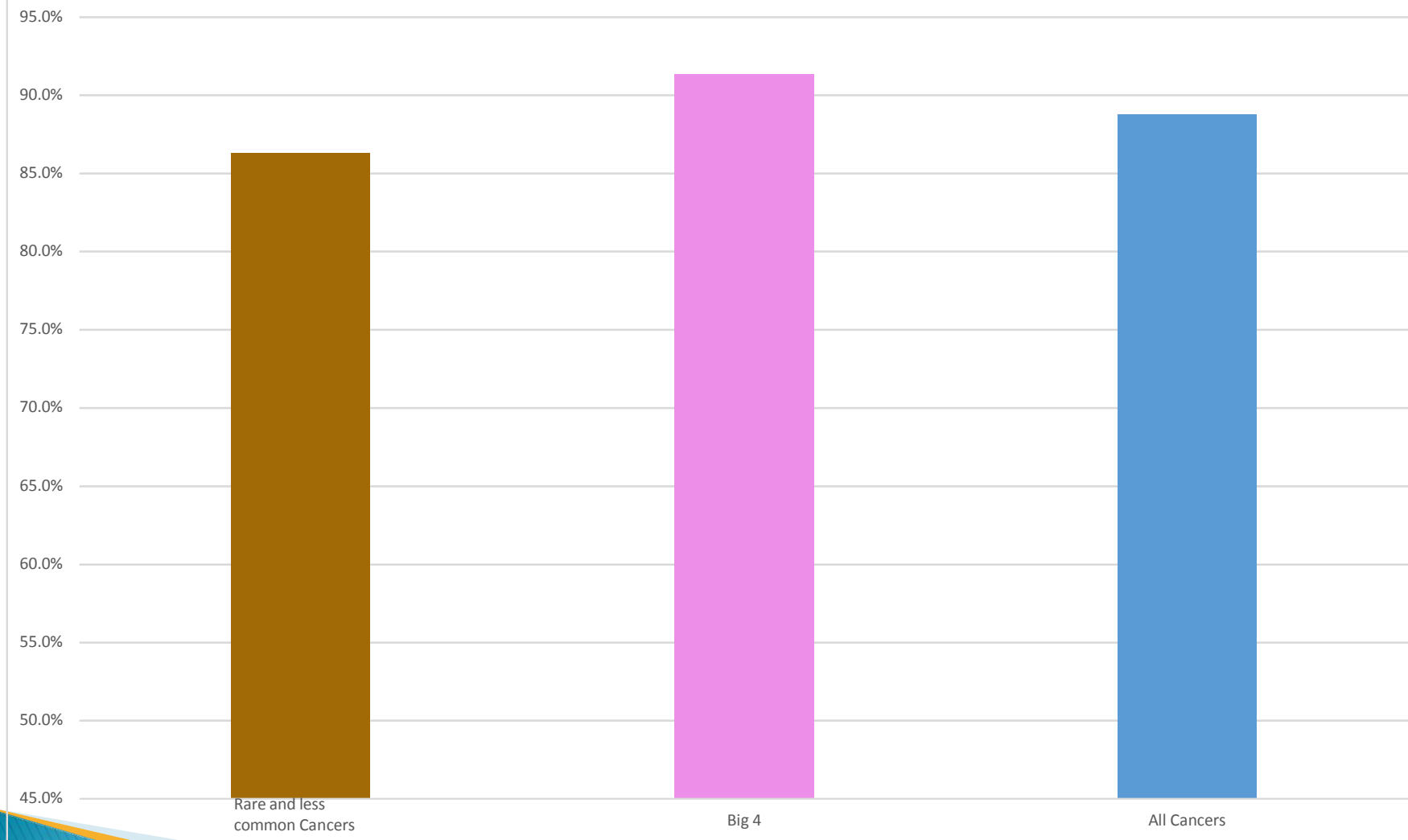


Q19 Patient told about side effects that could affect them in future



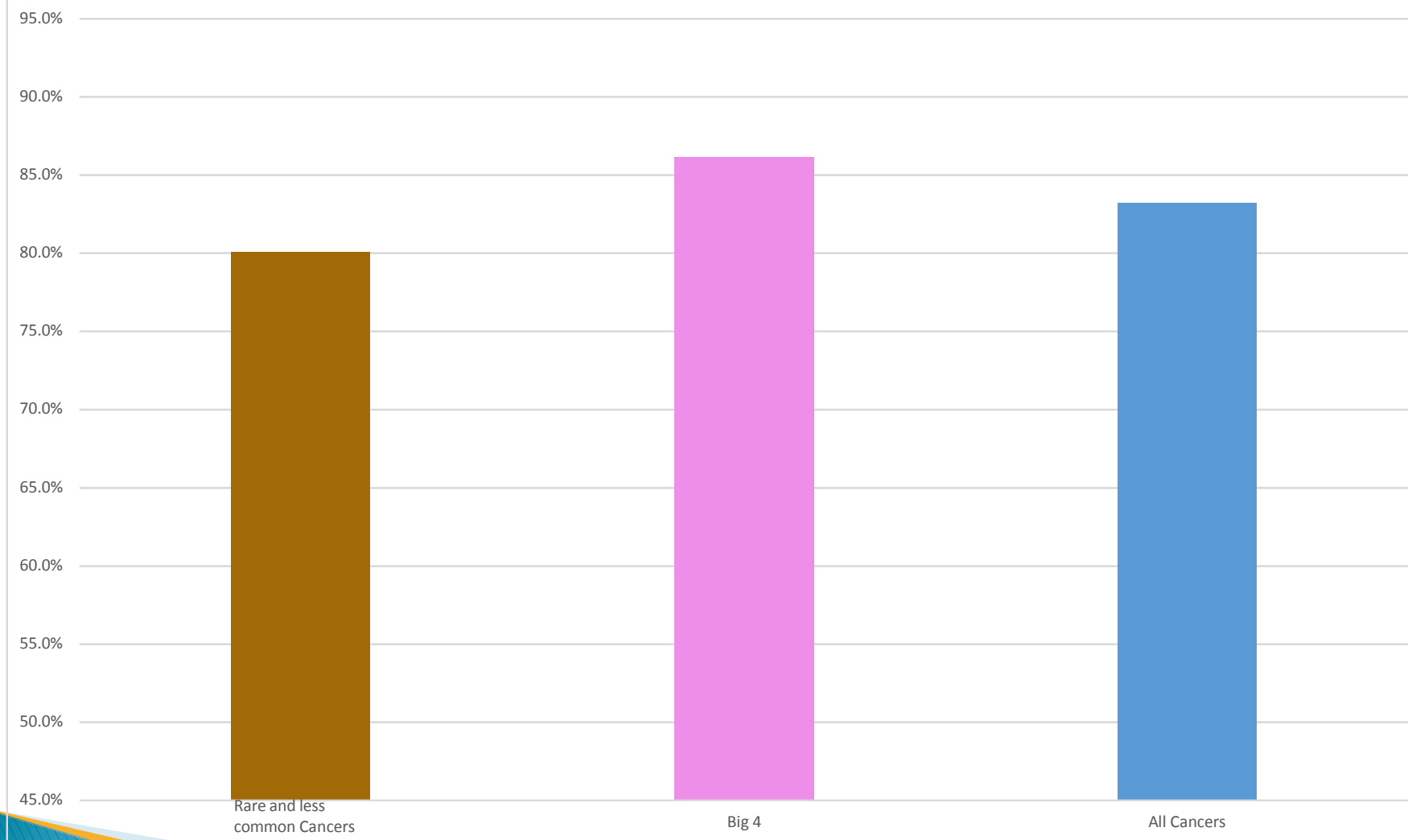


Q21 Patient given the name of the CNS in charge of their care



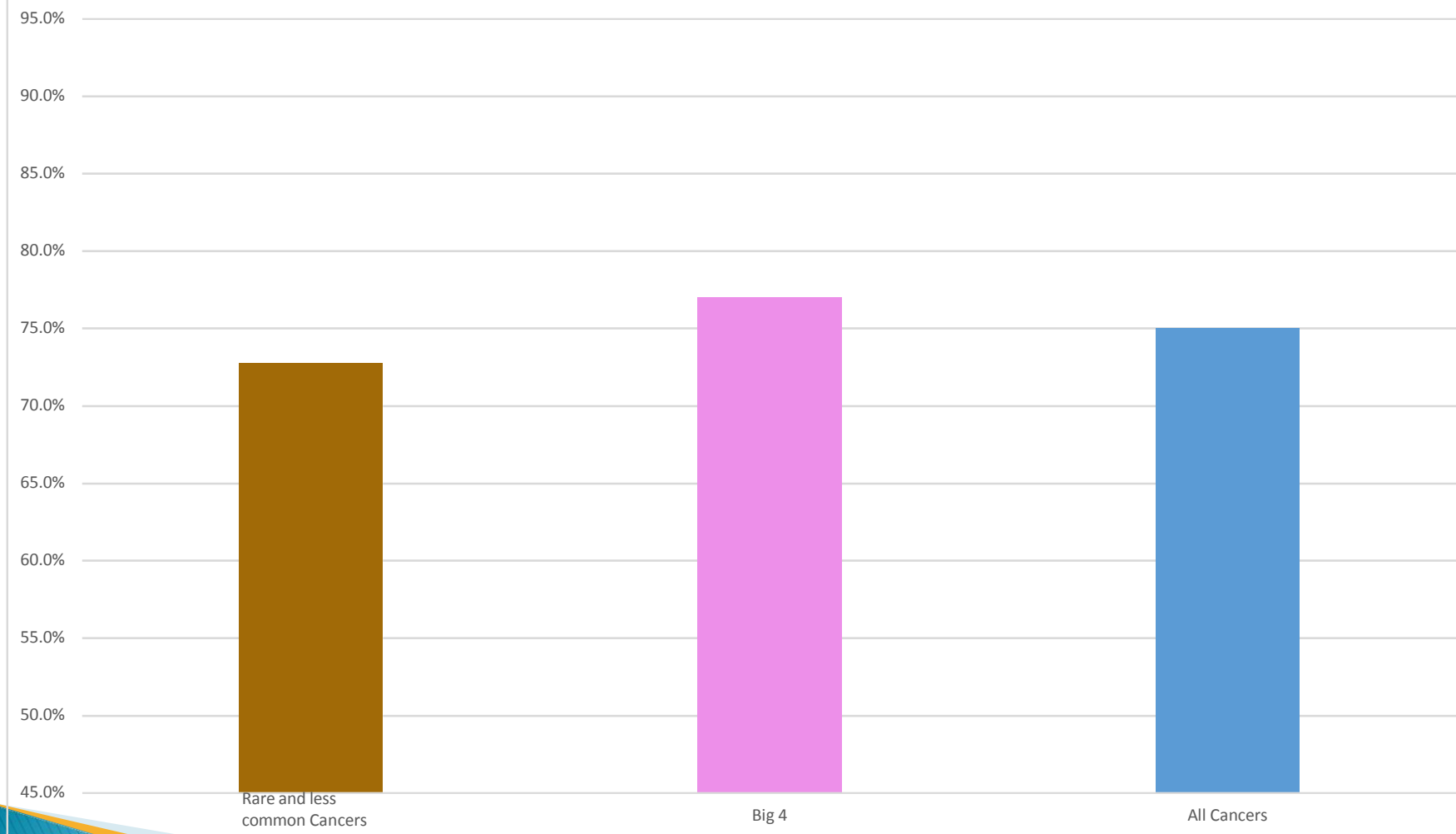


Q25 Hospital staff gave information about support groups



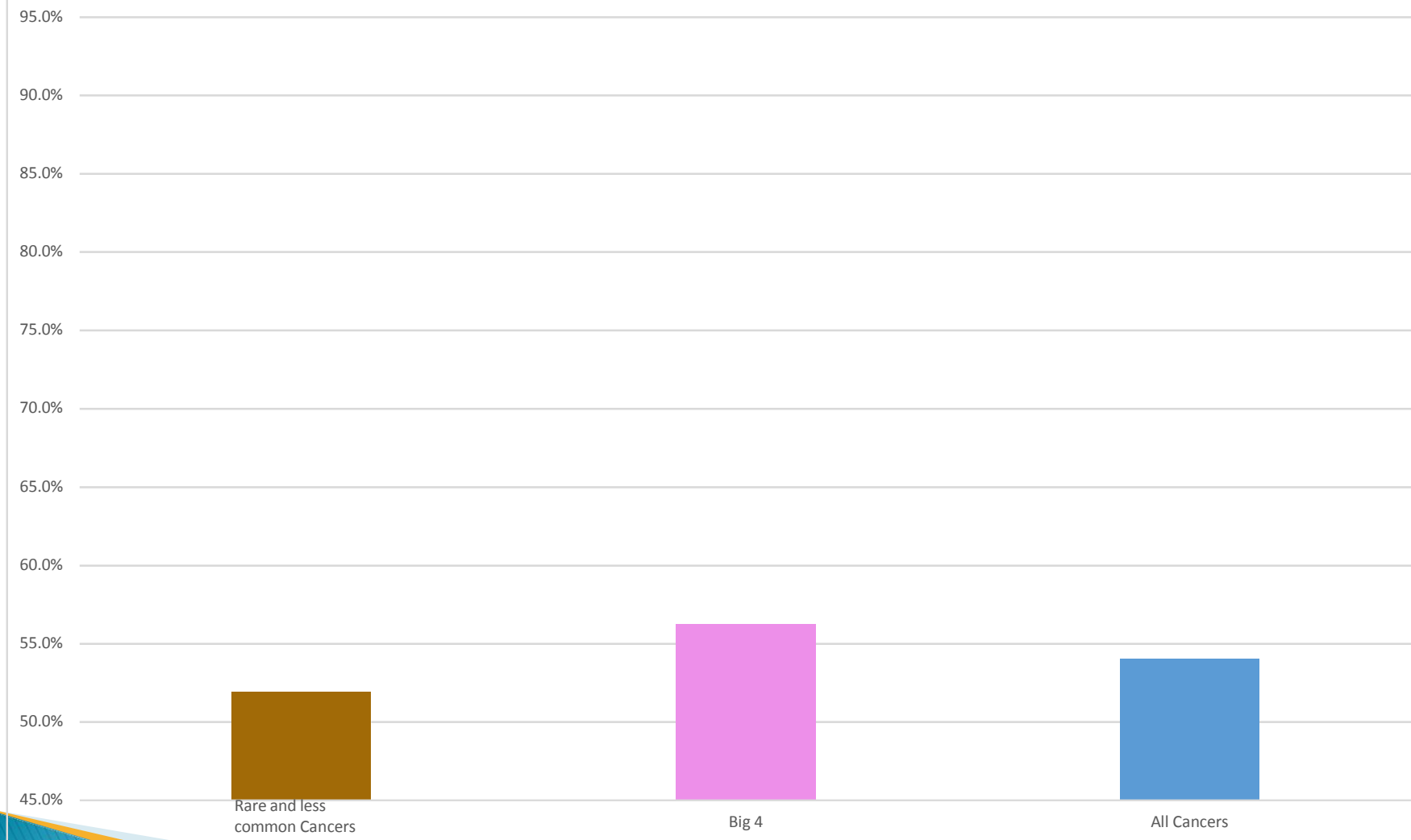


Q26 Hospital staff discussed or gave information about impact cancer could have on work life or education



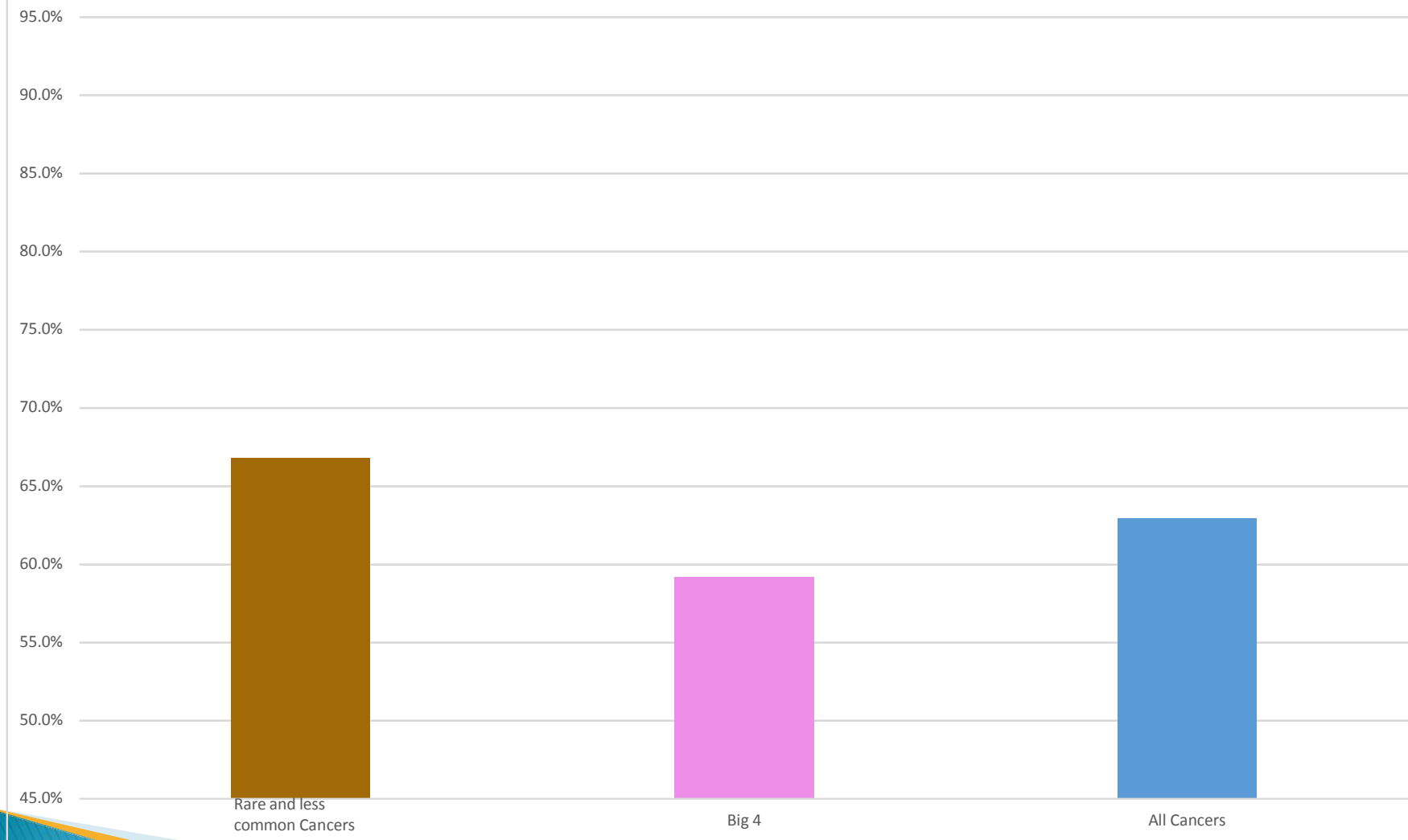


Q27 Hospital staff gave information on getting financial help



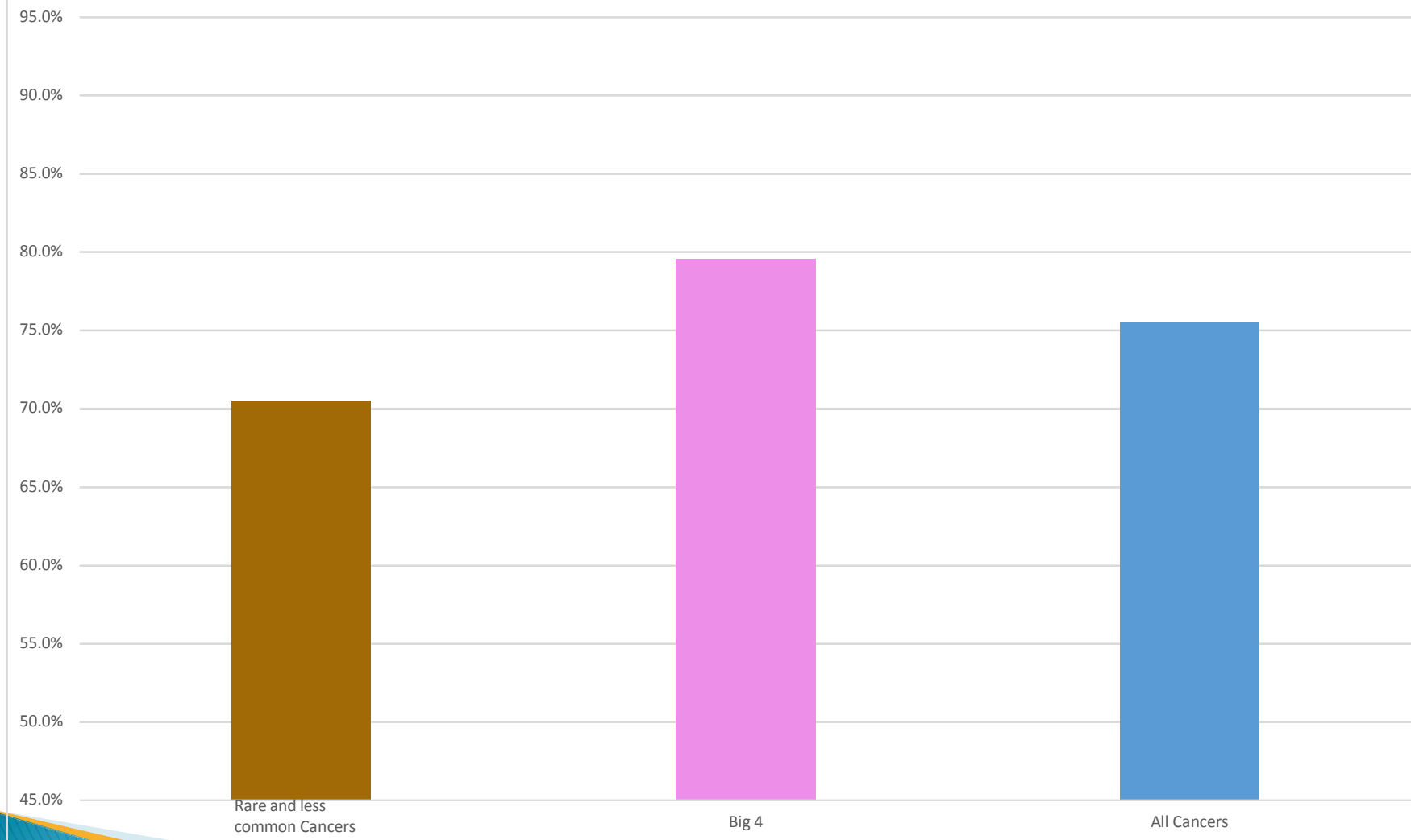


Q31 Patient went on to take part in cancer research



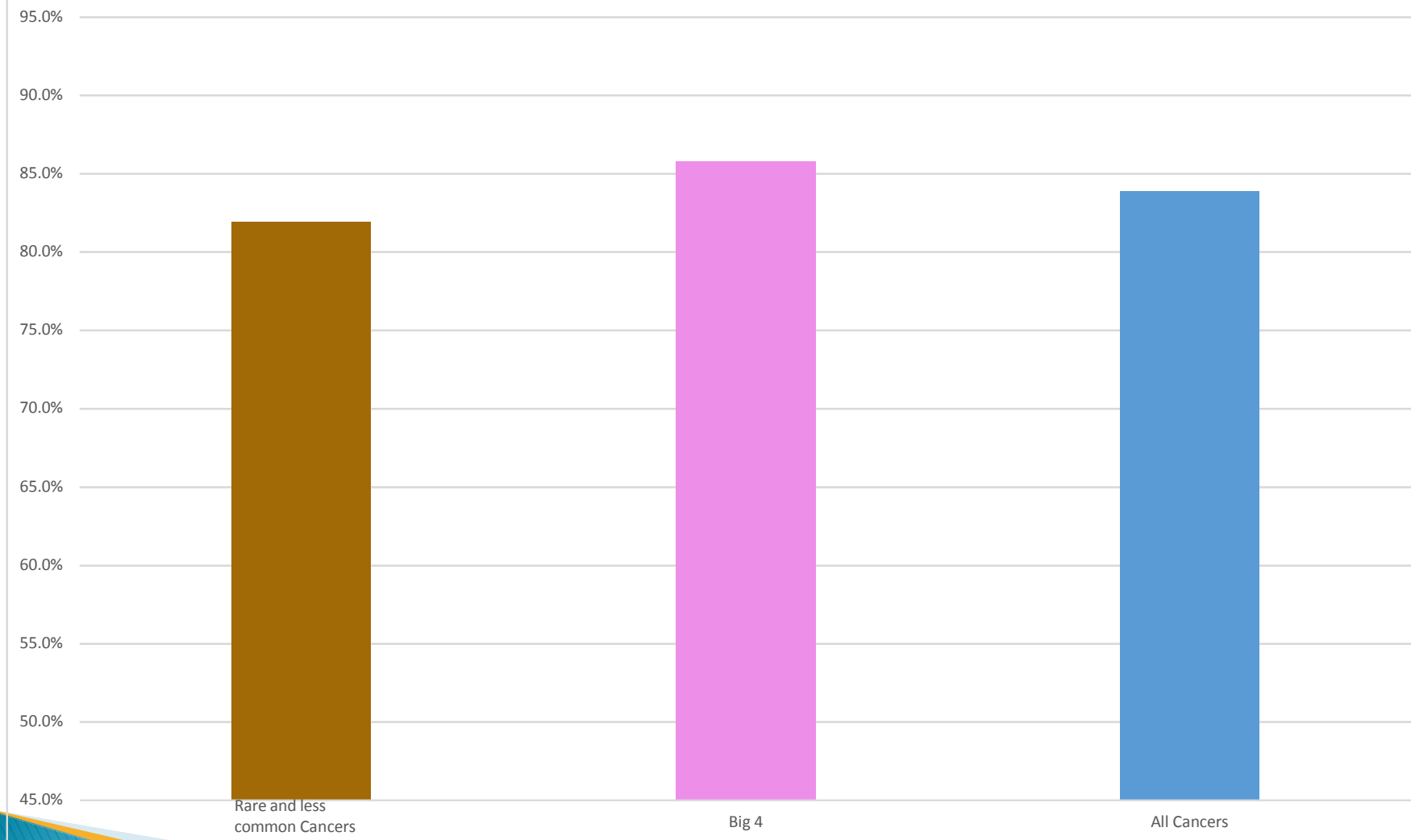


Q34 Given written information about operation beforehand



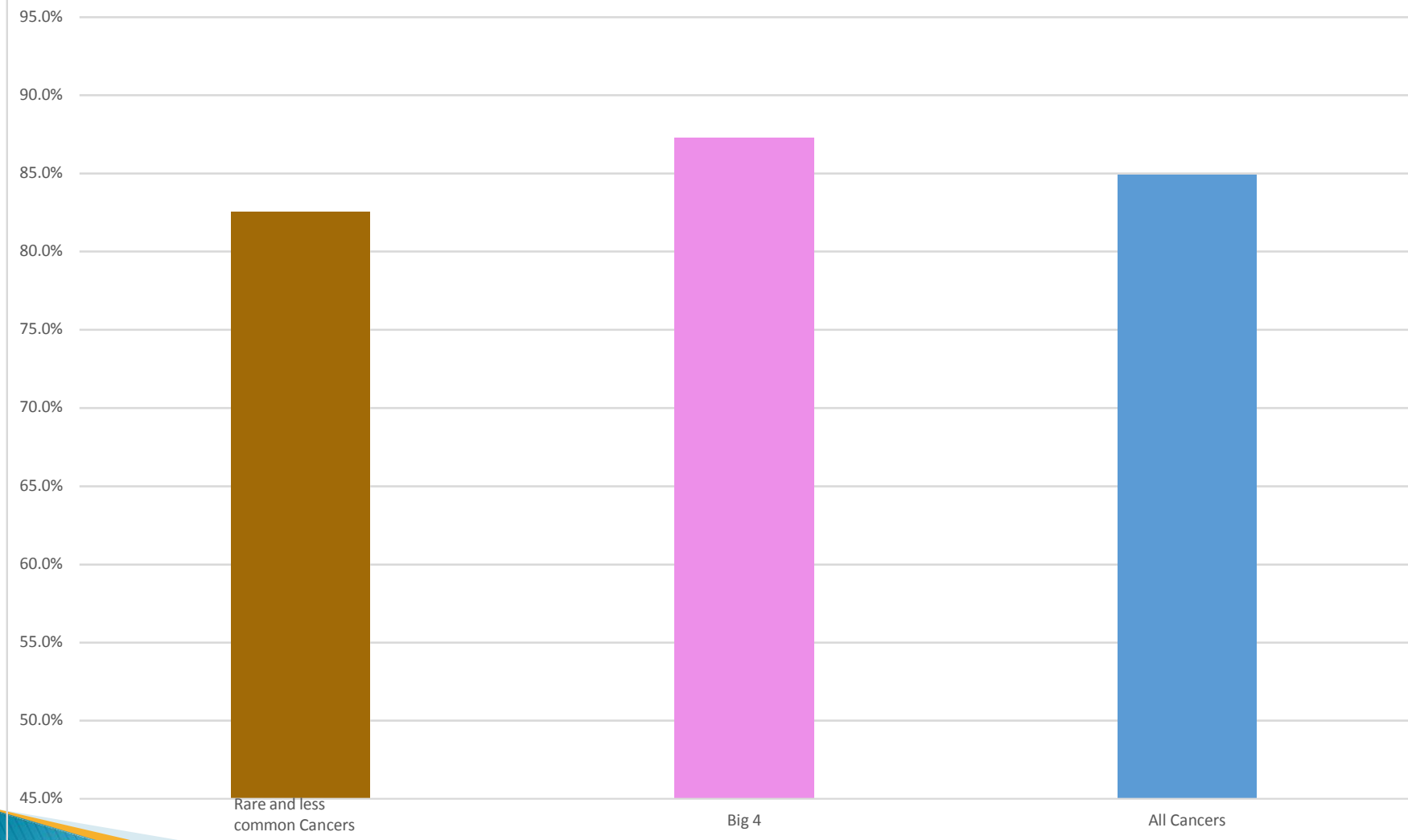


Q39 Doctors did not talk in front of patient as if they were not there



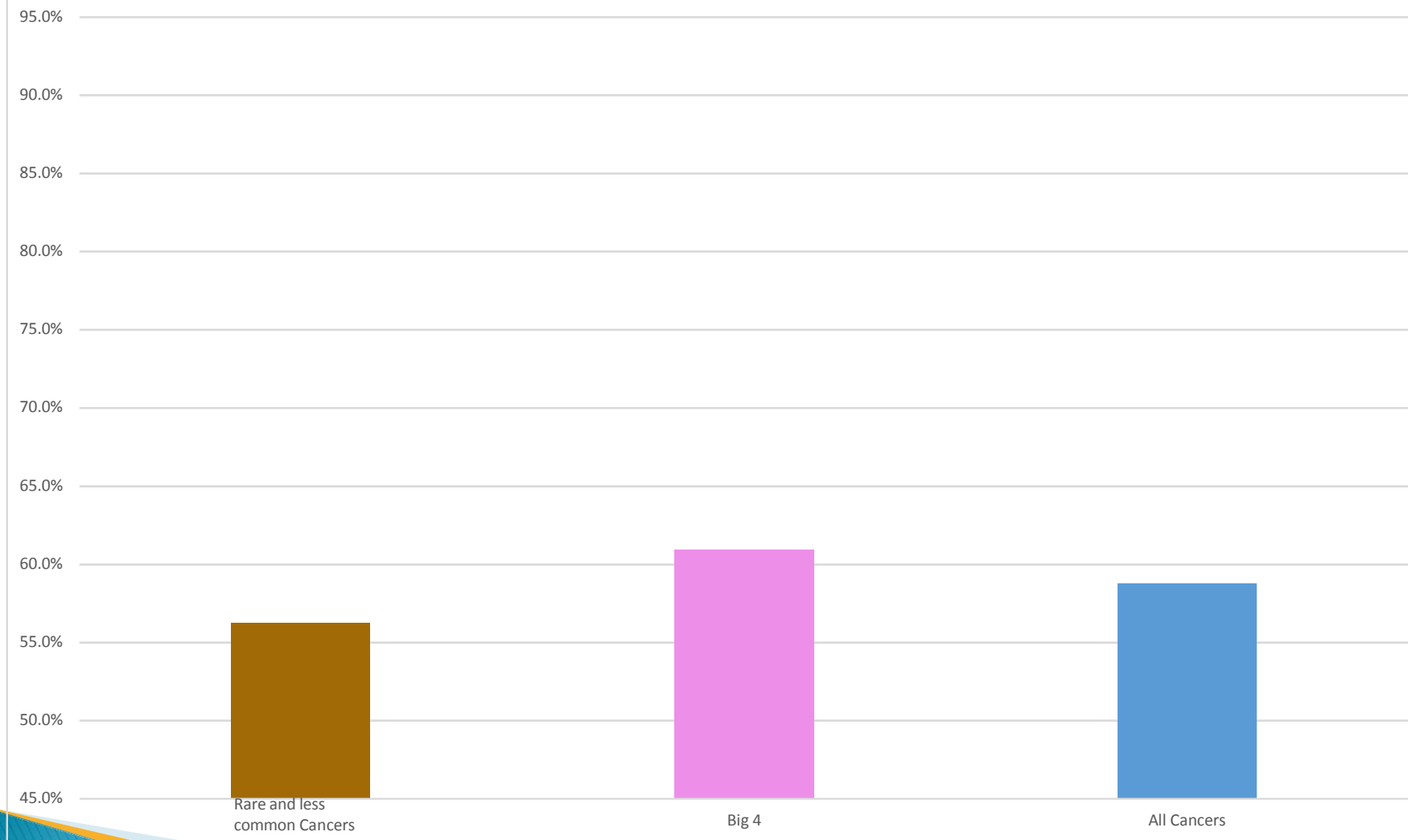


Q53 Given clear written information about what should / should not do post discharge





Q56 Patient definitely given enough care from health or social services



Conclusions



- ▶ In general, cancer patients' perception of their treatment and care is very positive, and improving
- ▶ The role of the Clinical Nurse Specialist is key: 89% of patients now say they are given the name of their CNS
- ▶ We know from our other work that this – and all of the information questions – are key to positive experience and positive outcomes
- ▶ There is significant variation on these information questions by tumour group
- ▶ Some of the poorer scores are around the transition from primary to secondary care, and the boundaries between health/social care
- ▶ Some groups of patients have less positive experiences
- ▶ Patients with rare or less common cancers have significantly worse experiences on virtually every question