National Cancer Patient Experience Survey 2013: Patients Shaping the Priorities for Sarcoma

Sarcoma Voices

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Quality Health

Purpose of the Cancer Patient Survey

- To give voice to all cancer patients – ability to shape services, correct problems, identify strengths
- Covers all cancers – 116,000 patients in 2013; 720 sarcoma patients replied
- We can identify within this patients with different types of sarcoma
- Key point: many patients with rarer cancers say their care and treatment is worse than those who have more common cancers (breast, prostate, colorectal)

Further analyses

- Differences between tumour groups:
  - Patients in the “Big 4” cancer groups (breast, colorectal/lower GI, lung, prostate) have generally more positive views than patients in other cancer groups
  - Wide ranges of scores top/bottom eg “given easy to understand information about the type of cancer they had” – Brain/Central Nervous System 54%; Prostate 85%
  - Sarcoma tumour group scores are significantly improved since 2012
  - Poorest scores by tumour group now Urological and BCNS
- As in 2012, no consistent differences found between inpatients and day cases.

- Impact of the CNS:
  - One of the most striking finding of the 2010, 2012, 2013 surveys
  - 2013- sig differences on every question bar one in the survey between those who have a CNS and those who don’t
  - Example: given easy to understand written information about operation: patients with a CNS 77%; without a CNS 52%
  - Poorer coverage of CNSs amongst over 75s, in all 13 tumour groups. Overall coverage of CNSs lowest in Urological (76.4%) – compared to Breast (93.4%)
  - Patients who started treatment more than 5 years ago less likely to have a CNS in every cancer group (in 2010, 2012, 2013)

Conclusions: Cancer Survey 2013

- Big improvements in services 2012-2013 seen by patients in a substantial proportion of Trusts – building on the very substantial improvements between 2010 and 2012
- Major differences between Trusts – huge variations from top to bottom performing
- Some kinds of patients less likely to be positive than others:
  - Patients in some tumour groups e.g. brain/cns, other cancers, outside so called Big 4. Sarcoma scores radically improved since 2012
  - Those without a CNS, concentrated in specific tumour groups and age groups
  - Those in London
  - Those in the most deprived areas
  - Patients from ethnic minorities
  - Patients who are not heterosexual
  - Younger patients under 25 and in some cases the over 75s
  - Women (on most questions but not all)
  - Patients with a mental health or LD condition
  - Patients initially diagnosed more than 5 years ago
- This pattern of response much the same in 2010, 2012, 2013
- These are independent variables and do not confound; casemix adjustment changes rank order of Trusts very little

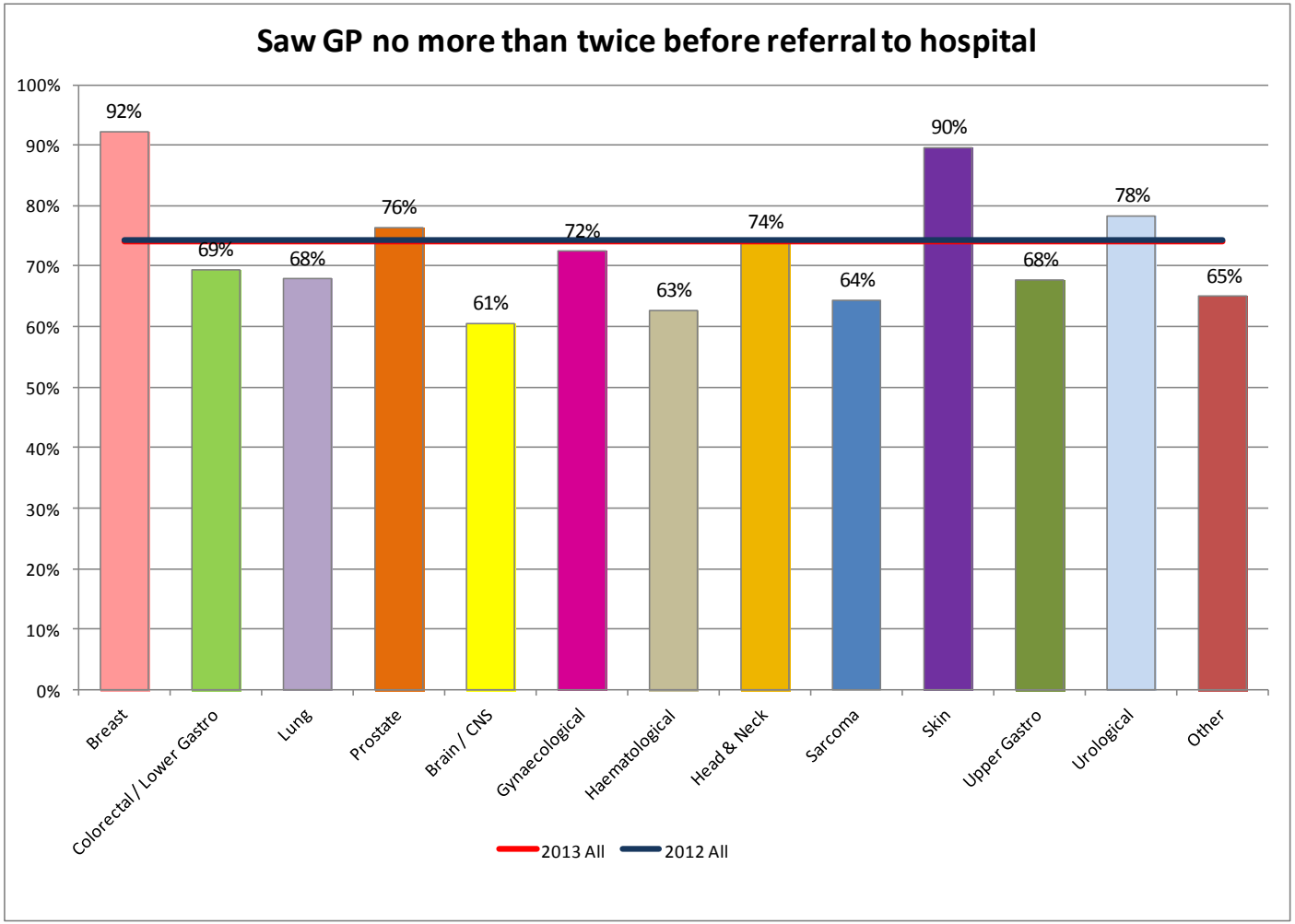
Rarer cancers – what's the score in 2013?

- Rarer cancers outside the big 4 definitely have poorer scores on most questions
- Some tumour groups never appear in the cluster of bottom performing tumour groups, e.g. Colo/LGI, Gynaecology, Head and Neck, Lung, Prostate
- Of the scored questions on which there are statistically significant differences between tumour groups, some rarer cancer groups had consistently poorer scores, e.g.
  - Urology is bottom scoring tumour group on 12 occasions (very different from Prostate)
  - BCNS is lowest scoring group 11 times
  - "Other cancers" (includes metastatic and cancers of unknown primary) lowest scoring 6 times
  - Skin: lowest scoring 3 times
  - Upper GI: lowest scoring 2 times
  - Breast: lowest scoring once
  - Sarcoma: lowest scoring once (radically improved from 2012)
  - Haematology: lowest scoring once

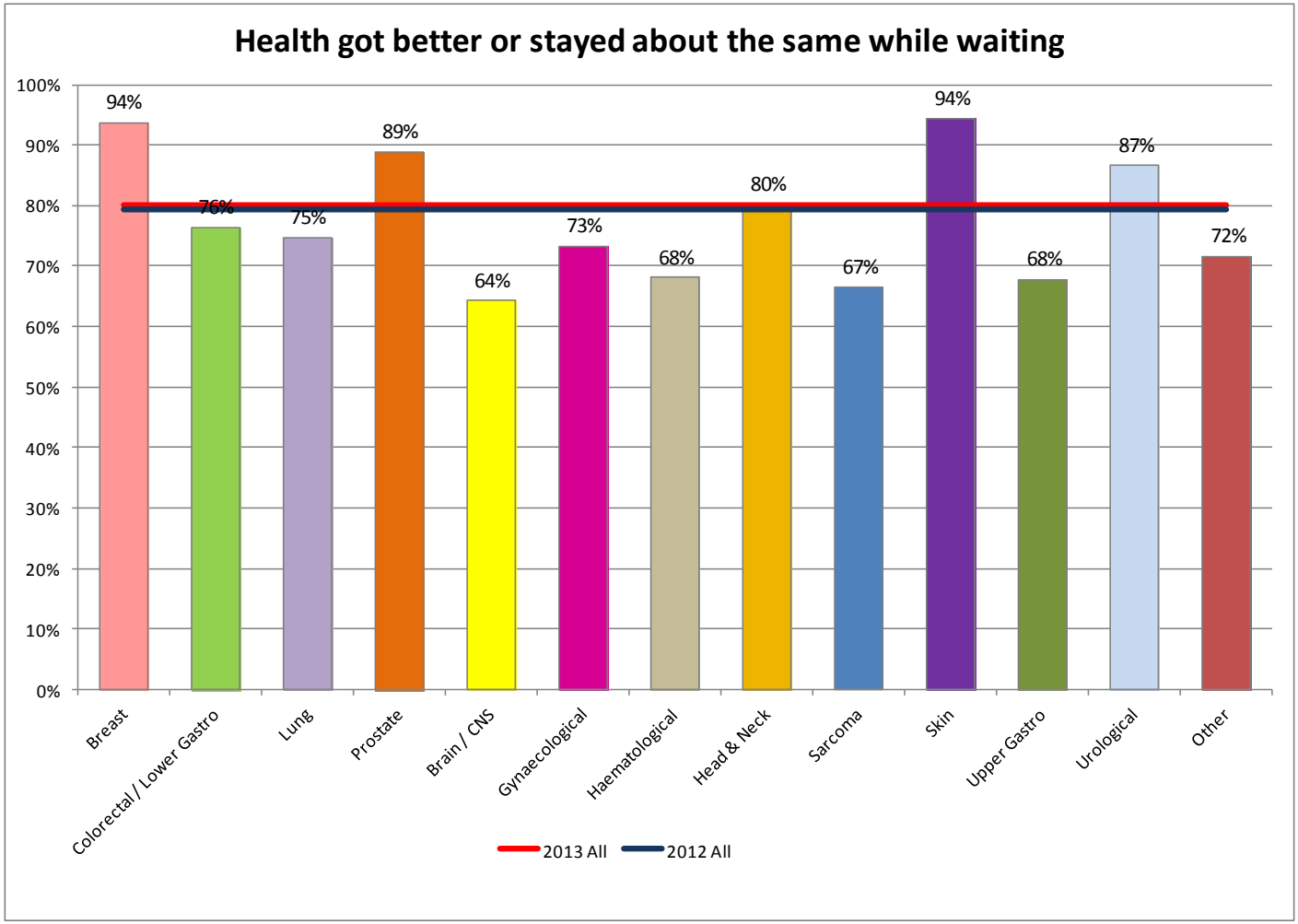
Key issues where some rarer cancers perform poorly

- Access fast: seeing GP only once or twice before referral
- Being told and understanding explanations of which cancer they had
- Choice of treatment issues, views taken in to account
- Given the name of a CNS – biggest single predictor of difference between patients
- Giving information on financial support and benefits
- Lots of information questions
- GP staff doing everything they could to support them post discharge: transition points between acute care and primary care
- Care plans – poor overall scores, and falling (one of the few)
- Being treated as a person rather than a set of symptoms
- Possible reason for patients falling through the net – complex pathways, who is in charge of care

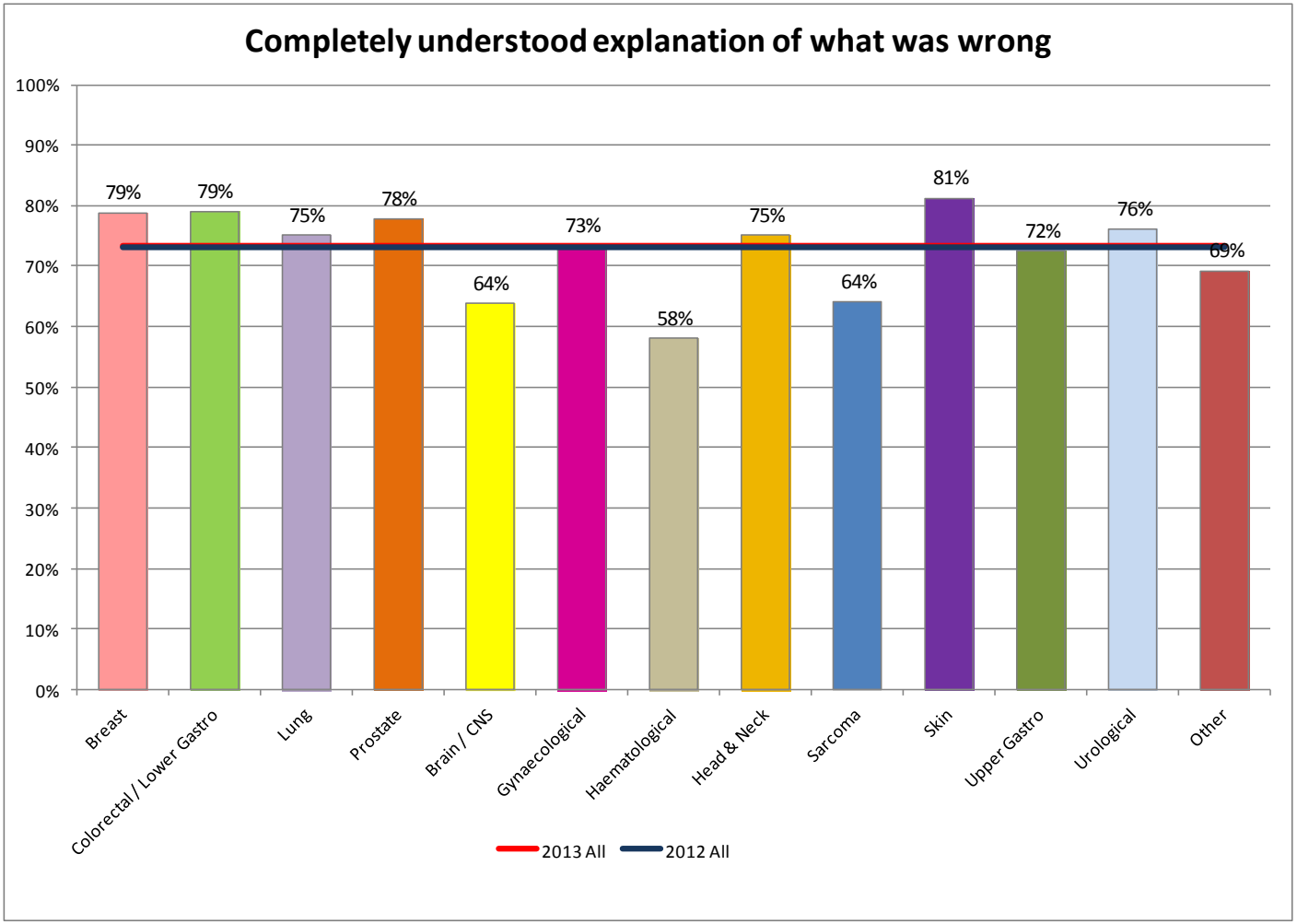
Saw GP no more than twice



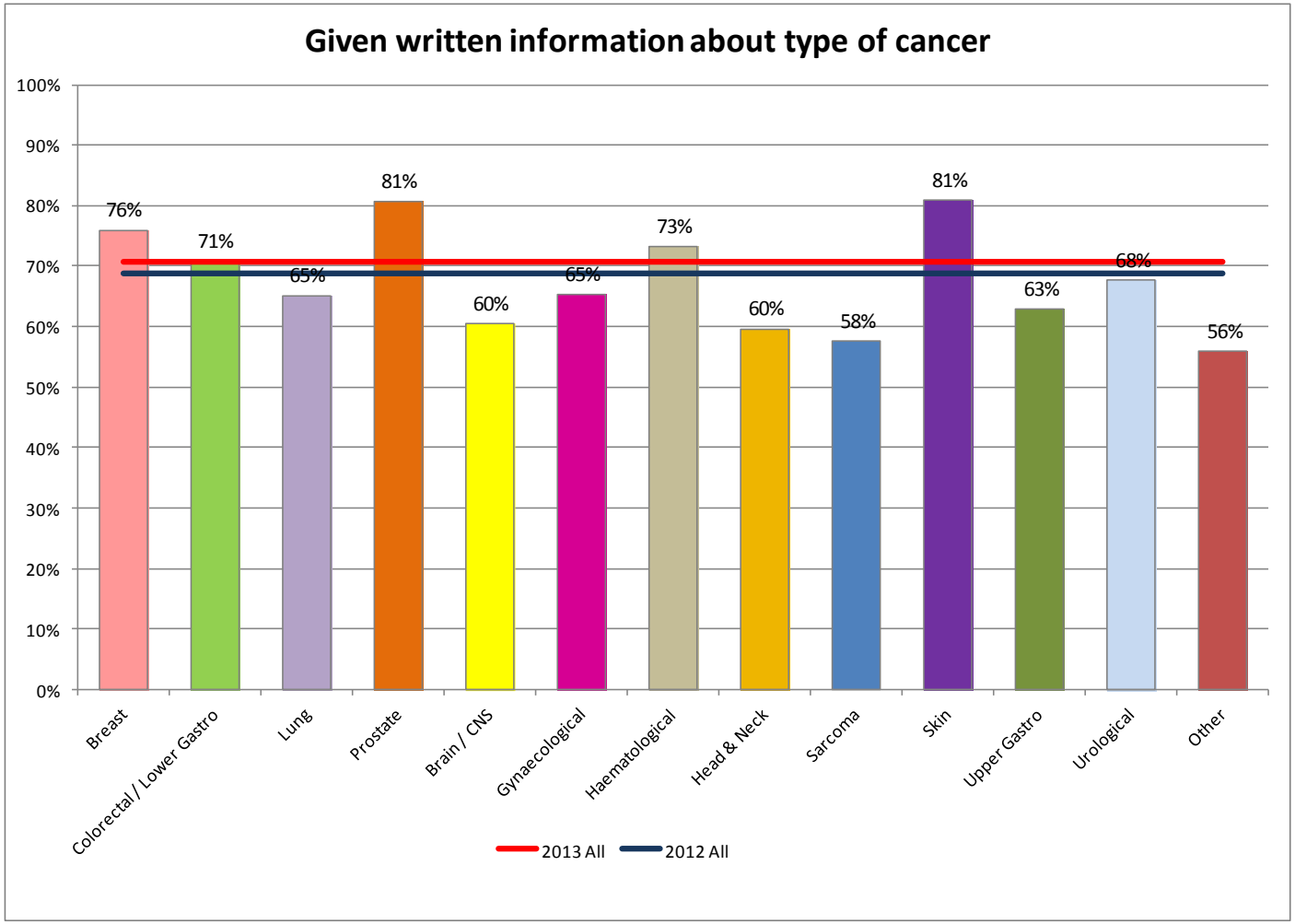
State of health while waiting



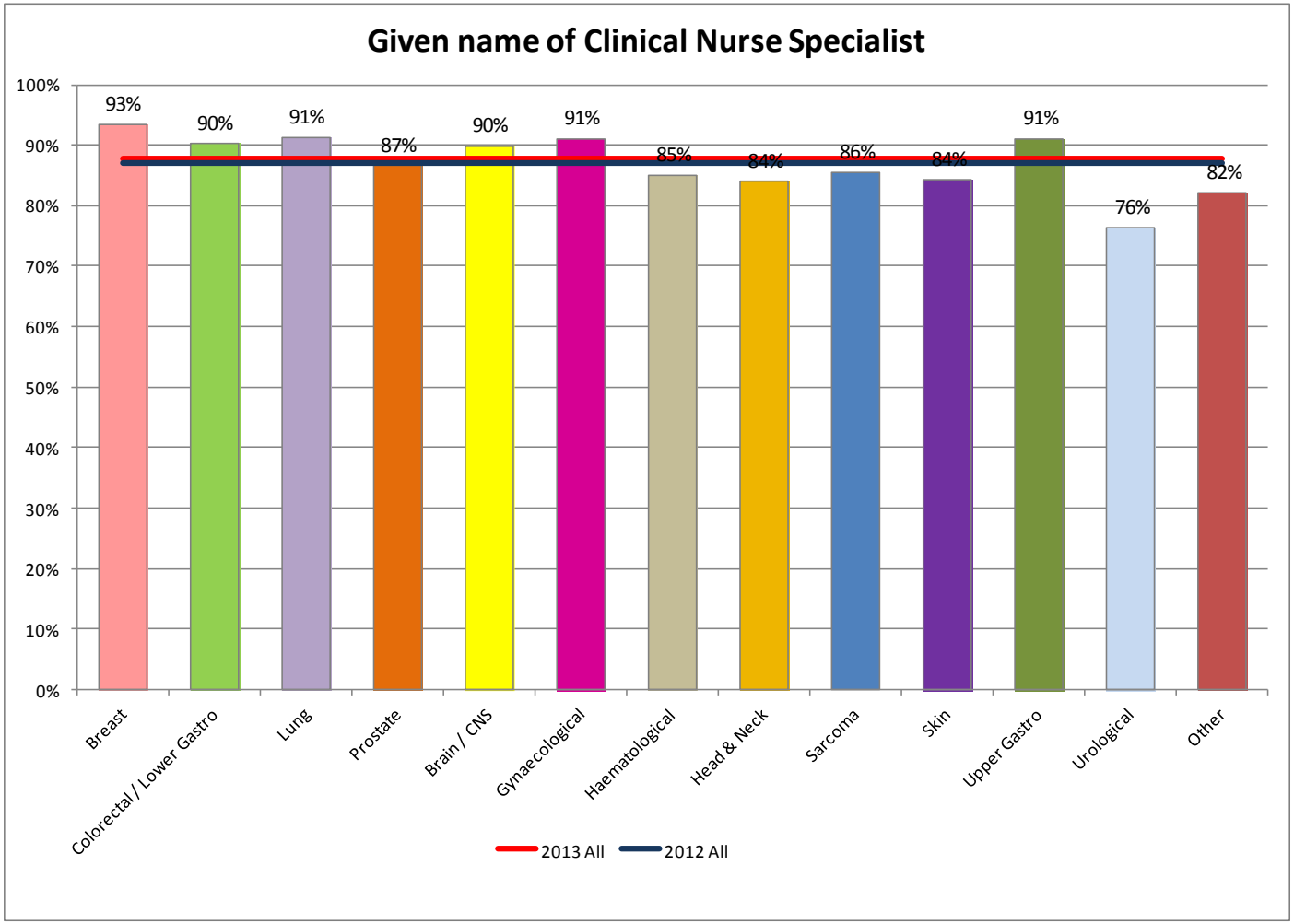
Explanation of what was wrong



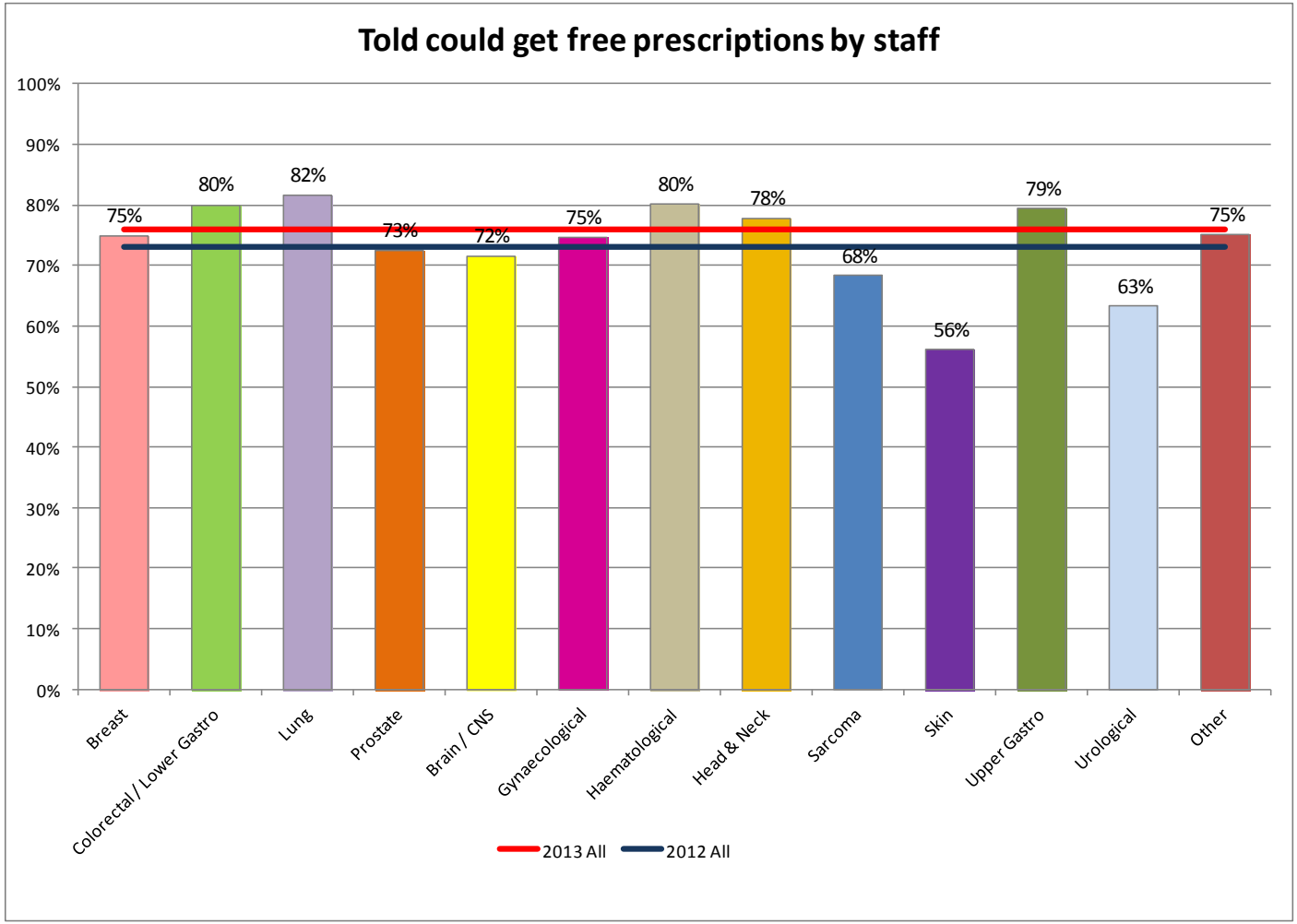
Written information about type



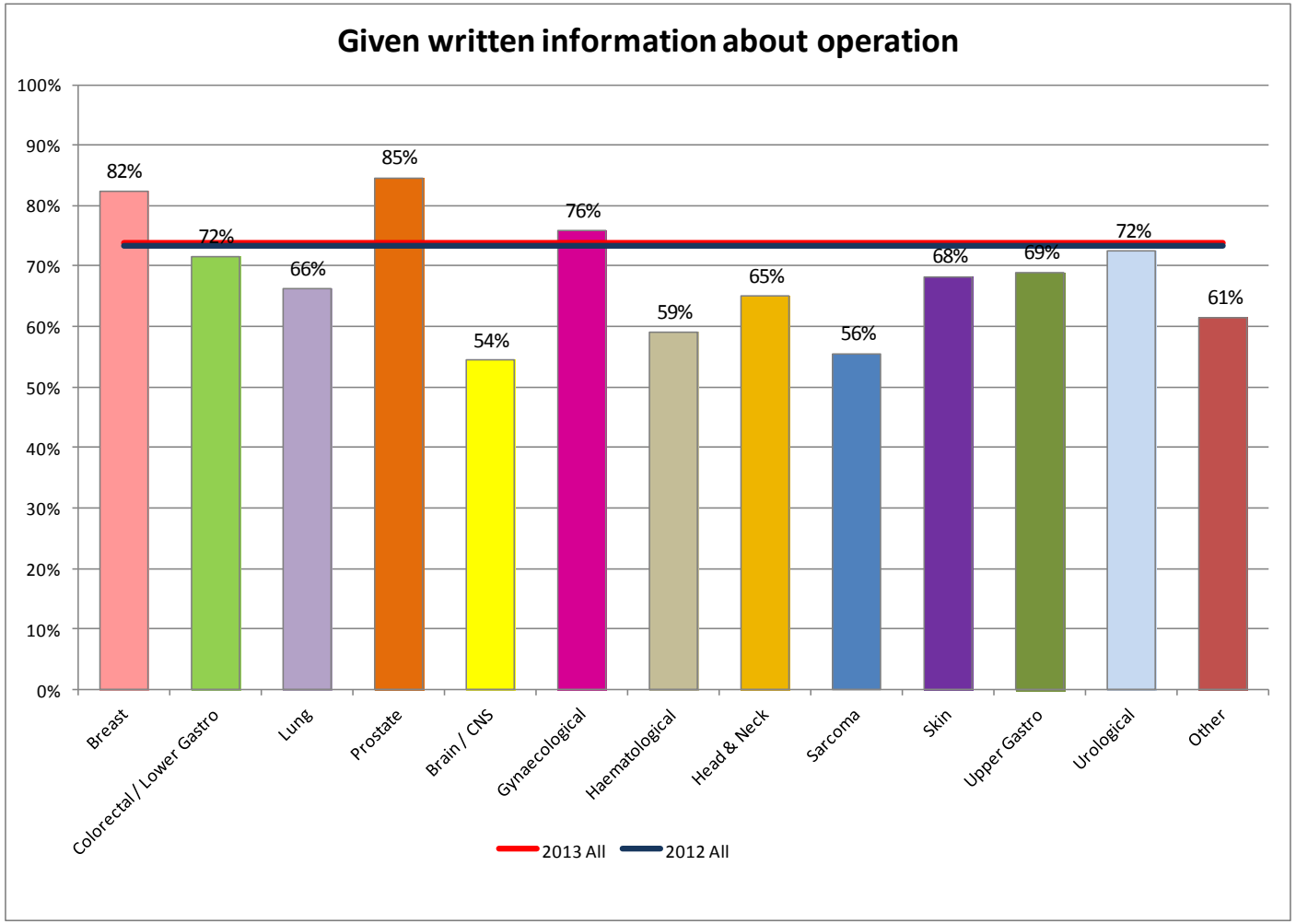
Given name of CNS



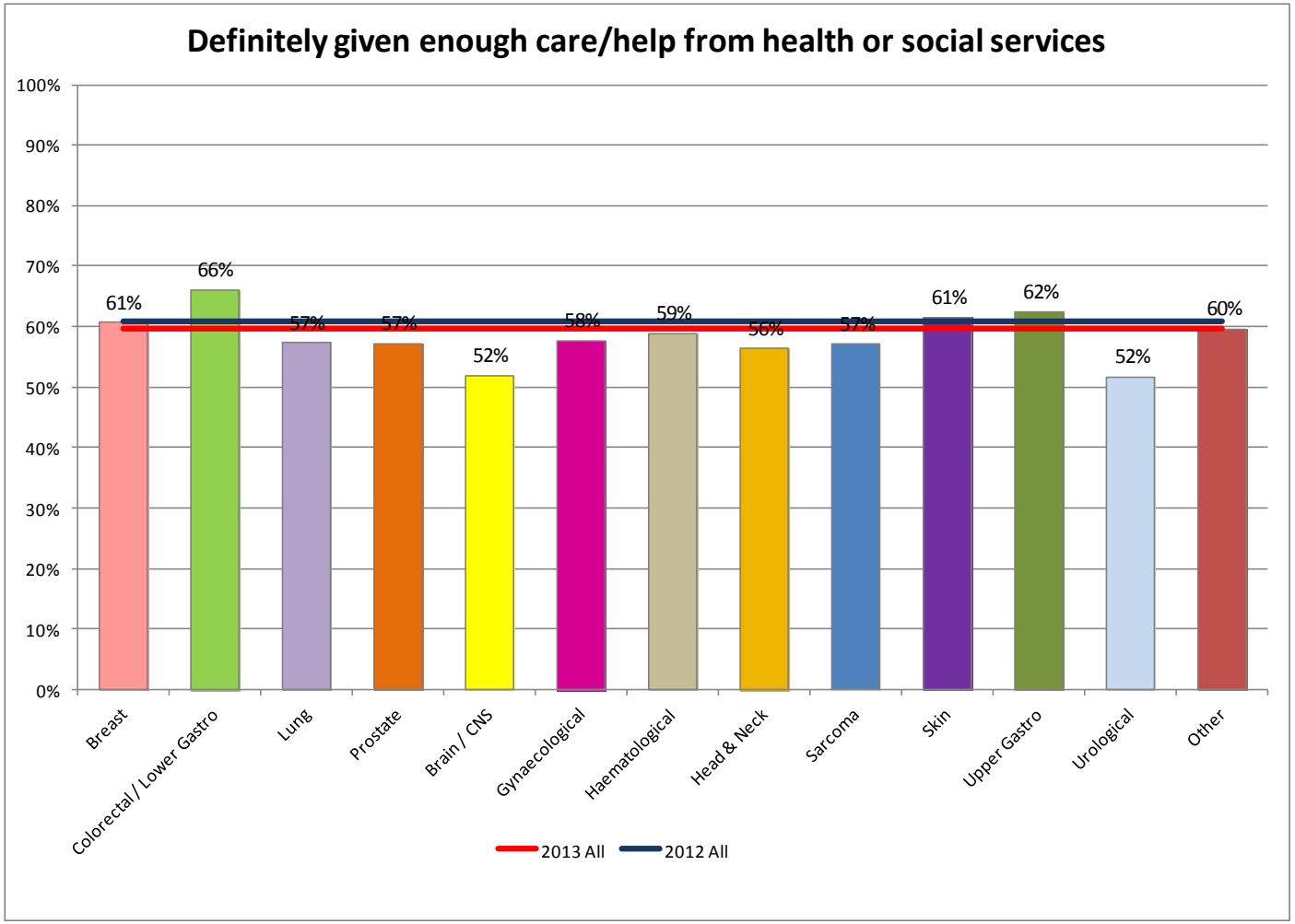
Told could get free prescriptions



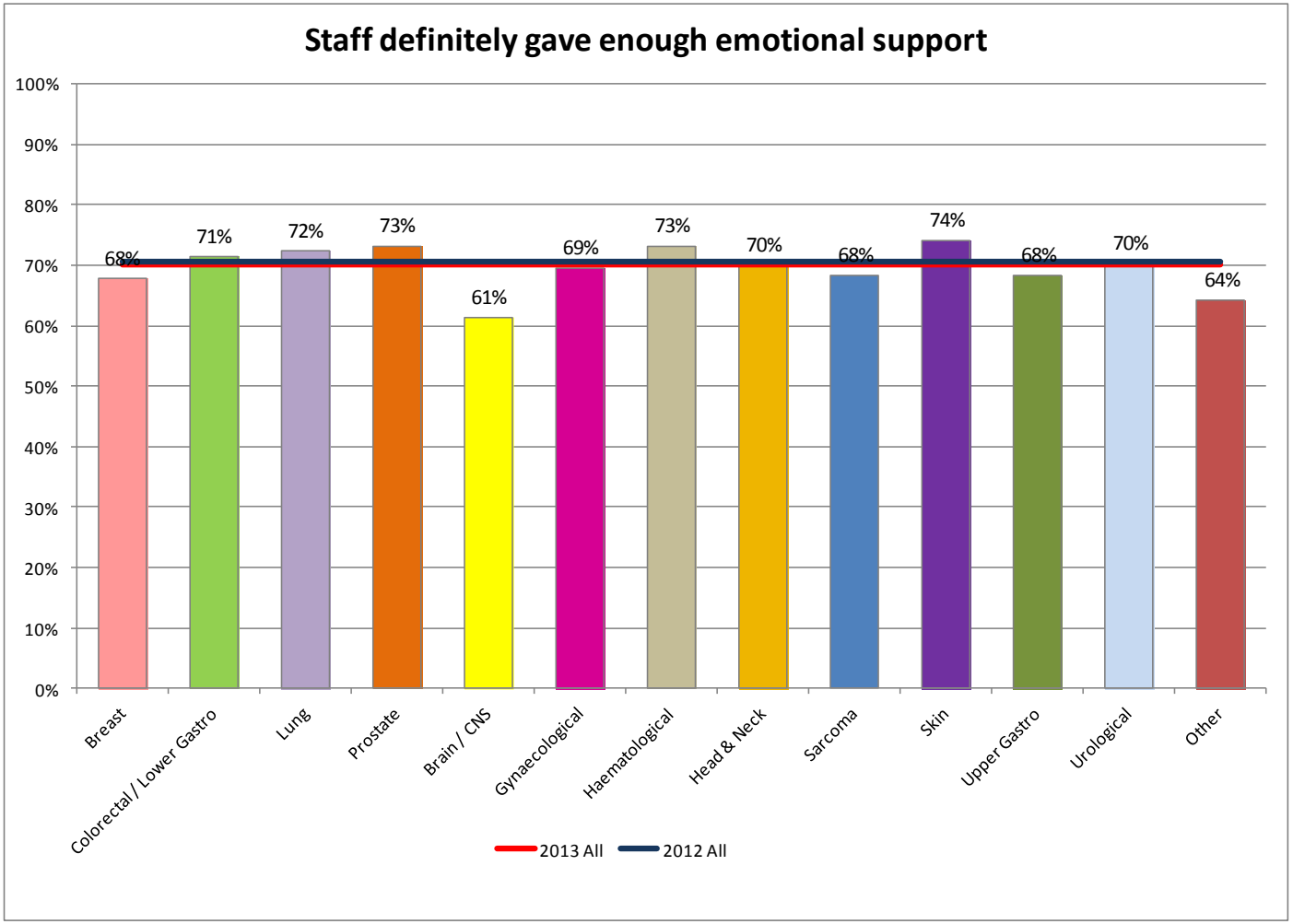
Written information about operation



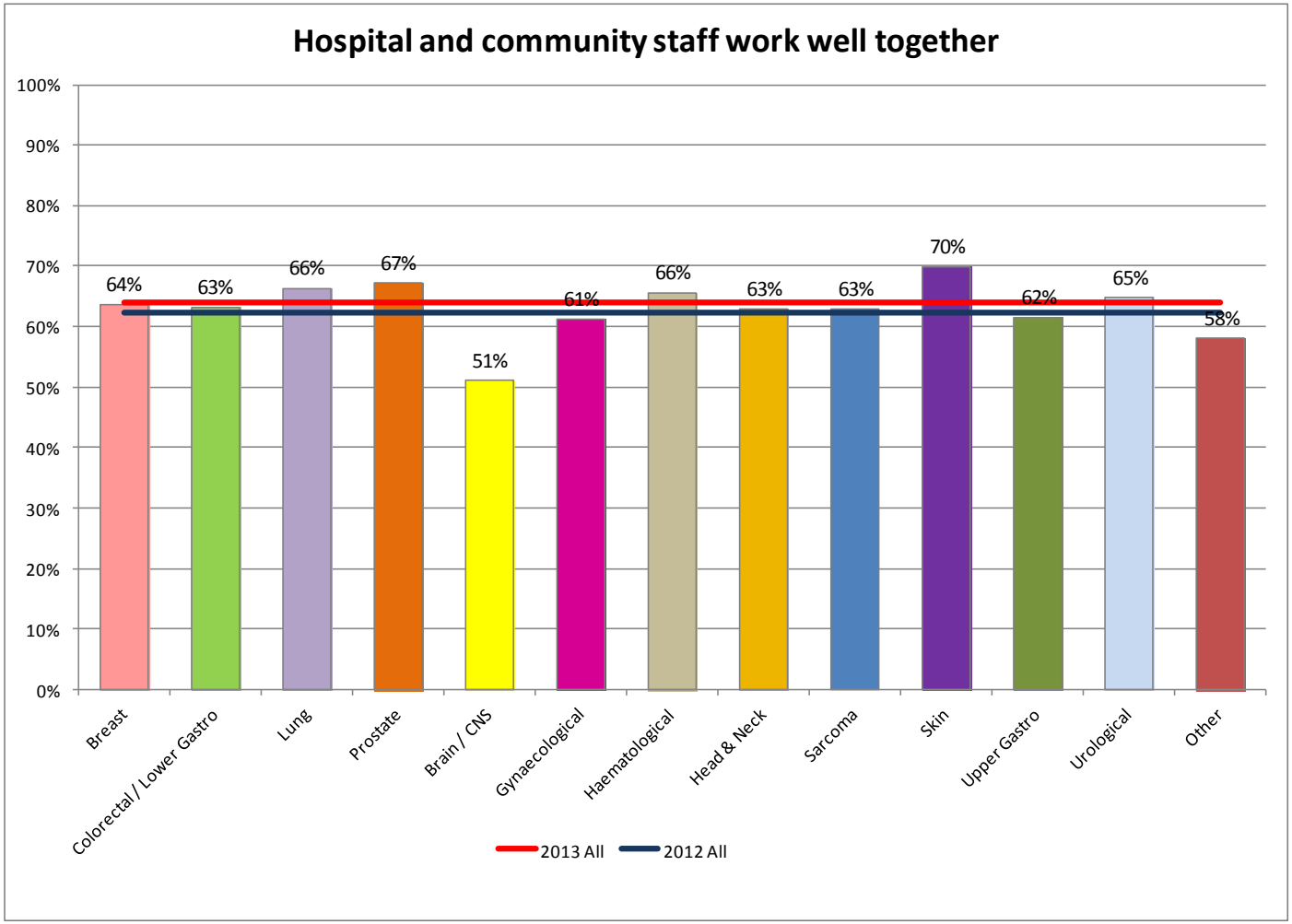
Care/help from health/social services



Given enough emotional support



Staff work well together



Sarcoma: Examples of Improved scores 2012-13

- Saw GP only once or twice before referral: 60% -65%
- Told they had cancer sensitively: 63% - 80%
- Given choice of treatment: 44% - 79%
- Told about free scrips: 51% - 68%
- Treated with respect and dignity by staff: 58% -85%
- Given easy to understand written information for post discharge phase: 58% - 78%
- GP given enough information about their condition: 62% - 96%

Differences between tumour groups 2013

Question in 2013		Lowest Score		Highest Score	
Q4	Health got better or stayed the same whilst waiting for first appointment with a hospital doctor	Brain / CNS	64%	Skin	94%
Q13	Completely understood the explanation of what was wrong with them	Haematological	58%	Skin	81%
Q14	Given easy to understand information about the type of cancer they had	Other Cancers	56%	Prostate and Skin	81%
Q34	Given written information about their operation	Brain / CNS	54%	Prostate	85%
Q40	Patient's family definitely had time to talk to the doctor	Urological	61%	Skin	74%
Q60	Staff definitely gave patient enough emotional support	Brain / CNS	61%	Skin	74%

The next steps for rarer cancers

- Develop written information where it does not exist, nationally available and usable: Sarcoma still low on info on type of cancer
- Use Early Symptoms Surveys data to identify key signs that GPs and primary care can watch out for
- Use training process effectively through multi disciplinary teams
- Recognise that there are wider corporate issues related to cancer services performance – e.g. staff numbers in key roles and what they do
- Use the CPES to interrogate those with rarer cancers – supplementary surveys are possible – Pancreatic in fieldwork now, Younger Persons and NET cancers surveys in development
- Coding issues not entirely resolved
- Work starting on comparing simple and complex pathways results from CPES
- Make your voices heard: All Party Parliamentary Group on Cancer; debates in Westminster Hall; social media; websites; lobby your MP; meetings with specialist Trusts treating Sarcoma; MAKE A RACKET!

National survey methodology

- 155 Trusts surveyed – all those providing adult cancer care
- Builds on the 2010, 2012 national CPES: one of the largest cancer survey programmes in the world
- 116, 490 patients surveyed: treated Sept-Nov 2012 in each Trust. Confidence interval +/- 0.3% at 95%
- Patient definition: inpatient or day case; ICD10 code in primary diagnosis field; C00-99 (excluding C44 and C84) and D05
- Trust level and National deduplication to prevent multiple surveys to individuals
- Questionnaire and cover letter asked patients to refer to treatment at the Trust named on cover letter

- Patients allocated to 13 DH approved tumour groups
- 2010, 2012, 2013 surveys all covered rarer cancers
- All 3 CPES used the word “cancer” explicitly
- Response Rate 64% (68,737): Response Rate range 74% to 33%. CQC inpatient survey c. 53% nationally
- Largest groups of respondents (% total):
  - Breast 20%
  - Haematological 17%
  - Colorectal/Lower GI 13%
  - Urological 10%
  - Prostate 8%
  - Lung 7%
  - Gynaecological 6%
  - Upper GI 6%

Key national findings

- Important differences of perception between patients in different cancer groups: rarer cancer patients have less positive views
- Patients overall responses positive – 80% or over on 31 of 63 scored questions
- On 14 questions, cancer patients scored 70% or lower: 2 were questions new in 2013 on research and information, and on future side effects of treatment. Lowest scores in 2013 as in previous years on some information questions, cancer research, ward nurses, care plans, cross-boundary co-ordination (acute-primary care)
- On comparable questions, cancer patients more positive than general hospital inpatients
- Patients diagnosed in last year more positive on 25 items than patients diagnosed 5+ years ago
- Significant variations by Trust: e.g. given name of CNS - range is 97% to 76% (narrower than 2012)
- 3 Trusts had no instances where patients rated them in bottom 20% of Trusts on individual questions: top Trust (Gateshead) had 44 appearances in top 20% of Trusts
- 40 Trusts had 20 or more instances where they were rated in the bottom 20% by patients: 21 of these were in London
- 76 of 155 Trusts showed significant improvements since 2012; 49% of Trusts improved their scores to some degree in 2013; 83% of Trusts improved 2010-12
- Many comparable questions between the 2012 and 2013 surveys
  - + Significant improvements on 31 of them
  - + Poorer scores on 4

Further analyses

- 2012-2013 comparison, examples of biggest improvements:
  - Hospital staff told pt they could get free scrips: up 3 points (and 8.3 points up on 2010)
  - Staff explained completely how operation had gone: up 2.1 points (and 3.8 points since 2010)
- Comparison with CQC inpatient survey: on 17 comparable questions, all but 1 score is higher than the national IP survey. Example:
  - Patient definitely involved as much as they wanted in decisions on treatment: cancer 72%; IP 55%

- Age differences:
  - 41 questions on which stat significant differences across age bands
  - Youngest age group 16-34 usually the least positive (on 23 of the 43)
  - But: 75+ group least likely to be given name of CNS (three years running in the CPES)
- Gender differences:
  - Smaller scale differences than other variables: 45 questions on which significant gender differences existed. Men more positive on 30 questions; women on 15
  - Men more positive about staff, privacy, respect and dignity, told enough, discharge, written information on type of cancer, free prescriptions
  - Women more likely to be given name of a CNS.

Further analyses

- Ethnicity:
  - On 22 questions, statistically significant differences between views of patients in different ethnic groups
  - On 20 of these 22 questions, white patients more positive than some ethnic minority patients
  - Black patients least positive on 3 items; Asians least positive on 11 items; Chinese/other ethnic least positive on 5 items
  - Examples of issues where EM patients more critical: information giving; confidence and trust in nurses; other issues on ward nurses; pain control; primary care support; and the overall rating of care
- Sexual Orientation:
  - Non heterosexual group aggregated (because of low numbers)
  - On 15 questions non heterosexual group are less positive than heterosexual patients (out of 16 where there are differences between heterosexuals and non heterosexuals)
  - Most of the 15 questions relate to communication and information and respect with which patient treated
- Long Term Conditions:
  - All LTCs aggregated
  - 54 questions on which stat sig differences between LTC and non LTC group; on 50 of these LTC patients are less positive
  - Those with MH or Learning Disabilities were the most critical groups

Further analyses

- Length of time since first treatment
  - On 25 questions, significant differences showing that patients who entered treatment 5+ years ago are less positive (replicating the finding in 2010 and 2012)
- SHA Analysis
  - 15 items on which sig differences between regions
  - On 11 out of the 15 items London is the worst performing SHA

- Social Deprivation
  - Significant differences between quintile 1 (least deprived) to quintile 5 (most deprived) on Index of Multiple Deprivation (IMD), on 40 questions
  - 18 of the 25 items where the most deprived decile patients are less positive relate to information giving
  - Also, some items on which Quintile 5 less positive relate to perceived feelings that patient being treated in offhand way (eg talking in front of the pt as if they were not there)
  - Some overlap between deprivation and ethnicity and age: quintile 5 has heavier concentrations of black/Asian and younger patients