**CANCER OF UNKNOWN PRIMARY (C77-80) PATIENT EXPERIENCE PERSPECTIVES COMPARED WITH ALL CANCERS IN THE NATIONAL CANCER PATIENT EXPERIENCE SURVEY (2012)**.

*Ref A: National Cancer Patient Experience Survey 2011/12. DoH Friday 17 August 2012*

The latest Cancer Patient Experience Survey (CPES) offers us an insight into cancer patients’ experiences (patients surveyed September - November 2011). It is interesting to isolate the CUP patients’ responses – taking CUP as ICD10 C77-80 - and compare them with the national ‘all’. This is presented below (I have the data shown by SHA, if wanted).

There are a large number of variables in the full data collection (which we do not have) that make the findings for the CUP community very general. In future it would be good to try and obtain access to the raw data to allow us to tease out more distinctions in relation to gender, in or outpatient, age, etc., and identify statistically significant differences robustly.[[1]](#footnote-1)

My interpretation of the data, that we do have access to, is as follows:

* **The survey shows, very obviously, CUP patients responses to be generally more negative than the national ‘all’**. Using the DoH’s benchmark of less than or equal to70% as being ‘less positive’ there are 23 ‘less positives’ for CUP versus 16 for ‘all’. The lingering aura of nihilism surrounding CUP may be a factor in the lower scores but it should be recognised that there is a significant variation between the ‘big 4’ collectively and the less common tumour sites. There are wider variations. For example: ‘Given easy to understand information about the type of cancer’ (Q14) is 11% worse for Sarcoma patients than for CUP patients. There are some questions where the particular nature of CUP could be seen to make a negative response unsurprising.
* **There are some ‘less positives’ that are easily rectified**. **Such things as: the lack of patient information and information about support groups**. CUP CNSs are effectively being introduced as part of the CUP MDT and ‘information’ features in Peer Review Measures. Knowing that many hospitals draw on the information we provide in preparation for Peer Review we should see improved scores in the future.
* Albeit that this is a national snapshot, and may not represent individual hospitals, **of particular concern to clinicians and nurses should be that: information and support, confidence and trust, and effective communication by doctors and nurses in relation to CUP patients are perceived to be significantly lower than the national ‘all’.**

It is not clear whether this important measure of patients’ experiences will continue in the future. CPES is not included in the *Clinical Commissioning Group Outcomes Indicator Set*.

John Symons

Director, CUP Foundation - Jo’s friends

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
| **National Cancer Patient Experience Survey 2011/2012** | | ***All CUP (C77-80)*** | ***%*** | *National All* | ***%*** |
| **SEEING YOUR GP** | |  |  |  |  |
| Q1. | Saw GP once/twice before being told had to go to hospital | 3736 | **68%** | 54682 | 74% |
| Q2. | Patient thought they were seen as soon as necessary | 4542 | 77% | 69208 | 83% |
| Q4. | Patient`s health got better or remained about the same while waiting | 4550 | 72% | 69120 | 79% |
| **DIAGNOSTIC TESTS** | | | | | |
| Q6. | Staff gave complete explanation of purpose of test(s) | 3847 | 82% | 58736 | 83% |
| Q7. | Staff explained completely what would be done during test | 4013 | 87% | 60302 | 86% |
| Q8. | Given easy to understand written information about test | 3236 | 87% | 46724 | 86% |
| Q9. | Given complete explanation of test results in understandable way | 4203 | 75% | 61576 | 78% |
| **FINDING OUT WHAT WAS WRONG WITH YOU** | | | | | |
| Q11. | Patient told they could bring a friend when first told they had cancer | 3709 | **70%** | 56933 | 72% |
| Q12. | Patient felt they were told sensitively that they had cancer | 4641 | 79% | 70132 | 83% |
| Q13. | Patient completely understood the explanation of what was wrong | 4635 | 71% | 70178 | 73% |
| Q14. | Patient given written information about the type of cancer they had | 3752 | **55%** | 60580 | 69% |
| **DECIDING THE BEST TREATMENT FOR YOU** | | | | | |
| Q15. | Patient given a choice of different types of treatment | 1586 | 77% | 24862 | 84% |
| Q16. | Patient's views definitely taken into account by doctors and nurses discussing treatment | 3960 | **66%** | 59838 | 70% |
| Q17. | Possible side effects explained in an understandable way | 4458 | 75% | 66331 | 75% |
| Q18. | Patient given written information about side effects | 4324 | 80% | 64984 | 81% |
| Q19. | Patient definitely involved in decisions about care and treatment | 4508 | **70%** | 67658 | 72% |
|  |  | ***All CUP (C77-80)*** | ***%*** | *National All* | ***%*** |
|  | **CLINICAL NURSE SPECIALIST** |  |  |  |  |
| Q20. | Patient given the name of the CNS in charge of their care | 4381 | 82% | 66714 | 87% |
| Q21. | Patient finds it easy to contact their CNS | 3288 | 74% | 52143 | 75% |
| Q22. | CNS definitely listened carefully the last time spoken to | 3468 | 90% | 56036 | 91% |
| **SUPPORT FOR PEOPLE WITH CANCER** | | | | | |
| Q23. | Get understandable answers to important questions all/most of the time | 3177 | 90% | 51209 | 91% |
| Q24. | Hospital staff gave information about support groups | 3535 | 77% | 51864 | 82% |
| Q25. | Hospital staff gave information on getting financial help | 2975 | **50%** | 39963 | 52% |
| Q26. | Hospital staff told patient they could get free prescriptions | 2243 | **70%** | 32749 | 73% |
| **CANCER RESEARCH** | | | | | |
| Q27. | Taking part in cancer research discussed with patient | 4397 | **37%** | 66445 | 33% |
| Q28. | Patient glad to have been asked about taking part in cancer research | 1611 | 95% | 21432 | 95% |
| Q29. | Patient not asked about taking part in cancer research would like to have been asked | 2584 | **59%** | 41747 | 53% |
| **OPERATIONS** | | | | | |
| Q31. | Admission date not changed by hospital | 1926 | 88% | 39749 | 90% |
| Q32. | Staff gave complete explanation of what would be done | 1888 | 85% | 38971 | 87% |
| Q33. | Patient given written information about the operation | 1716 | **62%** | 36082 | 73% |
| Q34. | Staff explained how operation had gone in understandable way | 1896 | 73% | 38987 | 75% |
| **HOSPITAL DOCTORS** | | | | | |
| Q36. | Got understandable answers to important questions all/most of the time | 2635 | 78% | 44663 | 82% |
| Q37. | Patient had confidence and trust in all doctors treating them | 2796 | 79% | 48256 | 85% |
|  |  | ***All CUP (C77-80)*** | ***%*** | *National All* | ***%*** |
| Q38. | Doctors did not talk in front of patient as if they were not there | 2802 | 79% | 48174 | 83% |
| Q39. | Patient`s family definitely had opportunity to talk to doctor | 2405 | **59%** | 40592 | 65% |
| **WARD NURSES** | | | | | |
| Q40. | Got understandable answers to important questions all/most of the time | 2496 | **69%** | 42264 | 75% |
| Q41. | Patient had confidence and trust in all ward nurses | 2789 | **63%** | 47997 | 69% |
| Q42. | Nurses did not talk in front of patient as if they were not there | 2792 | 81% | 48011 | 84% |
| **HOSPITAL CARE & TREATMENT** | | | | | |
| Q43. | Always / nearly always enough nurses on duty | 2781 | **55%** | 47742 | 61% |
| Q44. | Patient did not think hospital staff deliberately misinformed them | 2791 | 85% | 48086 | 87% |
| Q45. | Patient never thought they were given conflicting information | 2792 | 75% | 47976 | 79% |
| Q46. | All staff asked patient what name they preferred to be called by | 2781 | **55%** | 47860 | 56% |
| Q47. | Always given enough privacy when discussing condition/treatment | 2801 | 80% | 48166 | 84% |
| Q48. | Always given enough privacy when being examined or treated | 2809 | 93% | 48327 | 94% |
| Q49. | Patient was able to discuss worries or fears with staff during visit as much as they wanted | 2449 | **59%** | 41416 | 64% |
| Q50. | Hospital staff did everything to help control pain all of the time | 2483 | 81% | 41079 | 84% |
| Q51. | Always treated with respect and dignity by staff | 2800 | 79% | 48030 | 83% |
| **INFORMATION GIVEN TO YOU BEFORE YOU LEFT HOSPITAL & HOME SUPPORT** | | | | | |
| Q52. | Given clear written information about what should / should not do post discharge | 2625 | 77% | 45616 | 84% |
| Q53. | Staff told patient who to contact if worried post discharge | 2698 | 89% | 46552 | 93% |
| Q54. | Family definitely given all information needed to help care at home | 2339 | **55%** | 39521 | 60% |
| Q55. | Patient definitely given enough care from health or social services | 1835 | **61%** | 27075 | 61% |
|  | | ***All CUP (C77-80)*** | ***%*** | *National All* | ***%*** |
| **HOSPITAL CARE AS A DAY PATIENT / OUTPATIENT** | | | | | |
| Q56. | Staff definitely did everything to control side effects of radiotherapy | 2033 | 76% | 23416 | 79% |
| Q57. | Staff definitely did everything to control side effects of chemotherapy | 2946 | 82% | 40380 | 81% |
| Q58. | Staff definitely did everything they could to help control pain | 2944 | 79% | 39487 | 81% |
| Q59. | Hospital staff definitely gave patient enough emotional support | 3355 | **66%** | 47467 | 71% |
| Q61. | Waited no longer than 30 minutes for OPD appointment to start | 4315 | **66%** | 63159 | 70% |
| Q62. | Patient thought doctor spent about the right amount of time with them | 4464 | 94% | 65531 | 94% |
| Q63. | Doctor had the right notes and other documentation with them | 4325 | 94% | 63046 | 95% |
| **CARE FROM YOUR GENERAL PRACTICE** | | | | | |
| Q64. | GP given enough information about patient`s condition and treatment | 3835 | 93% | 57094 | 94% |
| Q65. | Practice staff definitely did everything they could to support patient | 3564 | **66%** | 48110 | 67% |
| Q66. | Hospital and community staff always worked well together | 4445 | **56%** | 66937 | 62% |
| **YOUR OVERALL NHS CARE** | | | | | |
| Q67. | Given the right amount of information about condition and treatment | 4580 | 86% | 69252 | 89% |
| Q68. | Patient offered written assessment and care plan | 3999 | **21%** | 58562 | 24% |
| Q69. | Patient did not feel that they were treated as a `set of cancer symptoms` | 4599 | 75% | 68733 | 80% |
| Q70. | Patient`s rating of care `excellent`/ `very good` | 4585 | 85% | 69276 | 88% |

1. Those who compare the table below with Ref. A will spot that n is up to 4,641 for CUP patients whereas the "other cancers" group shows n=1,138. As I understand it, this is because DoH required a primary diagnosis for their data collection; so the ‘others’ are site specific! [↑](#footnote-ref-1)