



## National Cancer Patient Experience Survey 2010 Output and Plans for 2011-12

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## National Survey Methodology

- 158 Trusts surveyed
- One of the largest cancer surveys in the world
- 109,477 patients surveyed: treated January-March 2010 in each Trust
- Patient definition: inpatient or day case; ICD10 code in primary diagnosis field; C00-99 (excluding C44) 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
- First survey to cover rarer cancers
- First survey to use word "cancer" explicitly
- Response Rate 67% (67,713): Response Rate range 77% to 39%. CQC inpatient survey 52% nationally
- Largest groups of respondents (% of total):
  - + Breast 21%
  - + Colorectal/Lower GI 16%
  - + Haematological 15%
  - + Urological 13%
  - + Prostate 8%

## 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 33 of 59 scored questions
- On 12 questions, cancer patients scored 70% or lower: 6 questions on information; 2 on nurses; 3 on integration of care across sectors and professions; 1 on wait times in OPD
- On comparable questions, cancer patients are 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 59%
- 12 Trusts had no instances where patients rated them in bottom 20% of Trusts on individual questions
- 34 Trusts had 20 or more instances where they were rated in the bottom 20% by patients: 18 of these were in London
- 10 comparable questions between the 2000 and 2010 surveys
  - + Improvements on 4 of them
  - + Poorer scores on 3
- Impact of CNS profound: some unequal access to CNS some older patients and some who started treatment 5 years ago

## Further Analyses

- 2000-2010 comparison, declining scores for comparable tumour groups:
  - + Completely understood explanation of what was wrong with them: 2000, 83%; 2010 76%
  - + Enough nurses on duty: 2000, 75%; 2010 62%
  - + Never received conflicting information: 2000, 88%; 2010, 79%
- Comparison with CQC inpatient survey: on 17 comparable questions, all but 1 score is higher than the national IP survey. Example:
  - + Patient given right amount of information about condition and treatment: cancer 87%; IP 78%
- Evidence of sharply declining scores on ward nurses
- Age differences:
  - + 42 questions on which stat significant differences across age bands
  - + Youngest age group 16-25 usually the least positive
  - + But: 75+ group least likely to be given name of CNS
- Gender differences:
  - + Smaller scale differences than other variables
  - + 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 21 of these 22 cases, white patients more positive than some ethnic minority patients
  - + Black patients least positive on 6 items; Asians least positive on 6 items; Chinese/other ethnic least positive on 9 items; mixed race least positive on 1 item
  - + 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
- Sexual Orientation:
  - + Non heterosexual group aggregated
  - + On 16 questions non heterosexual group are less positive than heterosexual patients
  - + 11 of the 16 questions relate to communication and information and respect with which patient treated
- Long Term Conditions:
  - + All LTCs aggregated
  - + 48 questions on which stat sig differences between LTC and non LTC group; on 45 of these LTC patients are less positive
  - + Those with MH or Learning Disabilities were by some distance the most critical groups

## 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 – on 41 questions
  - + Example: Given name of a CNS: "Big 4" 89%; others 79%
- Differences between inpatients and day cases: no consistent differences between IP and DCU patients. What differences exist are not large in scale
- Impact of the CNS:
  - + One of the most striking finding of the 2010 survey
  - + Sig differences on every question 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 71%; without a CNS 47%
  - + Poorer coverage of over 75s in some tumour groups: prostate; BCNS; haemo; H&N; sarcoma; skin; urology; other cancers
  - + Patients who started treatment more than 5 years ago less likely to have a CNS in every cancer group

## 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
  - + Example: Given name of CNS:
    - 5years+ Men 63%
    - 5 years+ Women 71%
    - 1-5 years Men 78%
    - 1-5 years Women 84%
    - Less than 1 yr Men 86%
    - Less than 1 yr Women 90%
- SHA Analysis
  - + 10 items on which sig differences between regions
  - + On 9 out of 10 items London is the worst performing SHA
- Social Deprivation
  - + Significant differences between decile 1 (least deprived) to decile 10 (most deprived) on IMD, on 37 questions
  - + 10 of the 21 items where the most deprived decile patients are less positive relate to information giving
  - + 4 of the 21 items relate to perceived feelings that patient being treated in offhand way
  - + Overlap between deprivation and ethnicity and age: decile 10 has heavier concentrations of black/Asian and younger patients

## Conclusions

- Major differences between Trusts
- Some kinds of patients less likely to be positive than others:
  - + Patients in some tumour groups e.g. sarcoma, brain/cns, other cancers, outside so called Big 4
  - + 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

## Management Recommendations

- Communicating with patients about their care and treatment
  - + All core members of the MDT should attend Connected course (Peer Review Measure)
  - + Courses organised through local Cancer Network: from April courses organised through NCAT)
  - + Courses funded nationally. Places limited but Trusts can commission additional courses at their expense
  - + 25 staff needed to be trained at Ealing on Connected course in Spring 2010
  - + All relevant information and contacts (NCAT team, local cancer network) can be found on [www.connected.nhs.uk](http://www.connected.nhs.uk)
- Improving cancer patients experience of having a key worker/CNS
  - + Trust should look at their provision of CNS's in relation to the median nationally: not out of line on Sarcoma
  - + Trusts can use audit tools such as 'Somerset' or 'Pandora' to establish where problems are
  - + Look at admin demands on CNS's to see if this reduces time supporting patients
  - + Look at time CNS's spend on managing units/ other staff, performing endoscopy etc to look at patient support time available
  - + Quality in Nursing. CNS in Cancer Care, Provision, Proportion and Performance: <http://www.ncat.nhs.uk/news/new-census-of-cancer->

## Management Recommendations

- Improving cancer patient experience on overall care and MDT focus:
  - + Ensure that each MDT aware of survey results at tumour level (where numbers allow)
  - + Reflect on the areas of lower scores within MDTs and agree what process changes could be made to improve
  - + Consider the MDT characteristics document and DVD and look at what can be applied to MDTs – see link
  - + <http://www.ncat.nhs.uk/our-work/ensuring-better-treatment/multi-disciplinary-team-development>
- Action to improve Trust performance could include:
  - + Monitor performance of clinical teams against NCPR measures. Provides good forward indicator for future performance on next National Cancer Patient Survey.
  - + Patient involvement in Internal Validation of clinical services for NCPR
  - + Patient engagement in the service by linking to the network Patient Partnership group
  - + Further info on the peer review programme <http://www.cquins.nhs.uk/>

## Management Recommendations

- National findings show clearly that young, over 75s, ethnic minorities, non heterosexuals, patients with rarer cancers, less likely to be positive
- Calibration of communication with these groups of patients is crucial:
  - + Role of CNS critical
  - + Simplicity of comms to the 1 in 4 who don't understand information about condition and treatment
  - + Information Prescriptions roll out important
- Use [www.cancerinfo.nhs.uk](http://www.cancerinfo.nhs.uk) - tumour specific patient information leaflets and has Cancer & Ethnicity Resource Portal (CERP)



## Key Elements of Trust Response

- Use the existing systems through NCAT
- Use peer review process
- Concentrate on training
- Address issues where Trusts are out of line with national data
- Get a simple action plan in place
- Composition of patient population was not a sufficient explanation of performance
- Some findings came out of analysis of poorest performing Trusts:
  - Mix of large and smaller Trusts were in the poorest performing group
  - Some Trusts did not have a Cancer Board (or similar) and were managing cancer only within MDTs
  - Complex pathways may have added to confusion amongst patients about who was in charge of their care
  - Some gaps in CNS provision and variability in effectiveness of CNS organisation



## 2011-12 Survey

- Prepare for repeat of survey in 2011/12
- Basic methodology the same – all Trusts, identifying patients through ICD10 and possibly other clinical markers
- Data capture period September-November 2011
- Fieldwork January – May 2012
- Reporting June – August 2012
- Each Trust will receive a local Report, showing progress since 2010, all cancers data compared to all Trusts/all cancers; and tumour group data/tumour group data nationally

