



DEPARTMENT OF HEALTH
Tackling Cancer:
Improving the Patient Journey

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1 In July 2000, the NHS Plan made it clear that health services were to be designed around the patient. In September of the same year, in his Foreword to the Department's Cancer Plan, the Secretary of State for Health said of the Plan that, "perhaps most important of all, it puts the patient at the centre of cancer care".¹ One of the four main aims of the NHS Cancer Plan was "to ensure people with cancer get the right professional support and care as well as the best treatments".

2 In 1999-2000 the Department of Health undertook a large scale national survey of cancer patients involving all NHS Trusts in England and covering six different types of cancer, to which over 65,000 cancer patients responded. That survey, published in 2002, provided a baseline to establish patients' experiences and opinions of the quality of service received in the period immediately before the implementation of the Cancer Plan. The survey found generally high levels of patient satisfaction in terms of issues such as dignity, privacy and respect, though it also identified areas for improvement.

3 Since that survey, substantial additional funding has been provided for cancer services. The NHS Improvement Plan in June 2004 emphasised that the NHS is to be "not just a national health service but also a personal health service for every patient".² The Department of Health and the NHS have introduced a range of measures to improve access, and good practice guidance has been set out to govern what needs to be done to make the patient experience as acceptable as possible.³ Most recently, the National Institute for Clinical Excellence issued guidance on improving supportive and palliative care in March 2004, though there has not been sufficient time for this to impact on the findings of this report.

4 We therefore carried out a national follow up survey of patients with the cancers that cause the most deaths, to gauge progress made in the four years since the introduction of the Cancer Plan (see Appendix 1). The survey was carried out in the early months of 2004 and involved responses from patients in 49 NHS Trusts with the four commonest cancers: breast, lung, bowel and prostate cancer. Between them, these cancers account for some 115,000 new cases each year. Some 7,800 patients were invited to participate in our survey, of whom 4,300 responded (55 per cent). The work is a companion to our two other reports on cancer services.⁴ We also visited hospitals and hospices to talk to clinical staff involved in cancer services and held focus groups and one-to-one interviews with GPs, nurses, patients and carers.

5 We also asked a small number of people with cancer, who volunteered, to talk about their experiences. These are recorded on the video disks attached to this report. The commentaries relate to the issues of interest in this report, and are intended to provide additional insight about what it is like to have cancer, over and above the statistical analysis in the report. The views expressed are those of the speakers and are not a part of the formal audit findings of this report.

6 Overall, we found encouraging progress had been made in most aspects of the patient experience, though for a minority of patients, elements of the patient experience were still not as good as they might be, such as communicating information, symptom relief and the lack of options for some patients in their last days. Prostate cancer patients continued to have a worse experience than those with other cancers and patients' experience of services in London remained less positive than elsewhere in England, even after taking into account other factors which could influence the patient experience.

7 The table overleaf provides an overview of the changes in patients' views since 2000, for questions identified as representative of the main themes within the national surveys of cancer patients.

¹ The NHS Cancer Plan, *A Plan for Investment: A Plan for Reform*, Department of Health (2000).

² Foreword by the Prime Minister, *The NHS Improvement Plan*, HM Government.

³ See National Audit Office Reports, *Tackling Cancer: Saving More Lives*, HC 364, Session 2003-04; and *The NHS Cancer Plan*, HC 343, Session 2004-05.

⁴ See National Audit Office Reports, *Tackling Cancer: Saving More Lives*, HC 364, Session 2003-04; and *The NHS Cancer Plan*, HC 343, Session 2004-05.

Key items from surveys of cancer patients' experience of treatment and care: comparison between 2000 and 2004

| | 2000 % | 2004 % |
|--|-----------|-----------|
| Patients did not perceive a worsening in their condition while waiting to see specialist | 74 | 80 |
| Patients told what was wrong with them with sufficient sensitivity and care (n/s) | 94 | 94 |
| Doctors or nurses discussed the purpose of treatment with patients, and patients completely understood the explanation | 82 | 86 |
| Patients found doctors' explanation of condition, treatment or tests very easy to understand | 62 | 68 |
| Patient always had trust and confidence in nurses | 79 | 81 |
| Patients with strong religious beliefs felt beliefs were taken into consideration by hospital staff | * | 91 |
| Printed information given to patient at discharge covered all the issues | * | 96 |
| Patient told about support or self-help group (n/s) | 61 | 60 |
| Patient had enough privacy during their examination at their last outpatient visit | 99 | 97 |
| A lot of confidence and trust in the doctor at the last outpatient appointment | 68 | 84 |

NOTES

- 1 Items are drawn from representative questions for each "theme" within the 2004 NAO Cancer Patient Survey (see Appendix 2).
- 2 For the items marked (n/s) the year-on-year change is not statistically significant.
- 3 Questions marked * not asked in 2000.

Cancer patients were broadly positive about their experience with GPs, the speed of diagnosis and how they were informed they have cancer

8 The experience of care of more than four in five patients in 2004 was positive prior to diagnosis and two thirds of patients stated that care received from their GP was "very good". Fifty eight per cent of patients were seen by a specialist within two weeks of referral from their GP compared with 46 per cent in 2000. The proportion of patients perceiving their condition as worsening during the wait fell from over a quarter in 2000 to a fifth in 2004. Patients referred urgently by their GP are now seen almost universally by a specialist within two weeks, but a significant minority of patients diagnosed with cancer are not referred urgently.

9 More than nine in ten patients considered they were told bad news with suitable sensitivity and more verbal and written information about diagnosis of cancer was communicated to patients, with greater success and sensitivity, than in 2000. Similar proportions understood the explanation given by clinicians of what was wrong with them and approved of the length of consultations. In future, more patients will be given a record to consider after the consultation. Patients who received printed information about their diagnosis were happy with it, and it was provided more often than in 2000. Nevertheless, four in ten cancer patients did not receive it. Patients without English as a first language have particular problems with receiving suitable information.

Cancer patients' experience of care given by hospitals improved since 2000 but there are still gaps in supportive and palliative care

10 Patients and their carers were more involved in care and treatment decisions than in 2000, and patients reported better communication about their condition, treatments and tests, although older patients and those with prostate cancer reported less positive experiences. Understanding of side effects improved significantly after 2000, but one quarter of patients said they either had less than a full understanding, or the issue was not discussed with them.

11 Discussions with patients about how treatment had gone were seen as broadly satisfactory, but a fifth of patients reported that their understanding had not been complete. Most patients were not told how to complain and some had difficulty in getting a satisfactory result when they did so, particularly breast cancer patients.

12 Almost all patients reported receiving sufficient respect, privacy and dignity during their hospital stay in 2004, though there remained concerns for a small minority around respect and dignity and privacy during discussions with hospital staff about their condition. Most patients felt they were treated respectfully and sensitively but the means of accessing religious support was not clear to a number of patients.

13 Patients largely gave positive responses regarding the nature of the care they received from hospital doctors and nurses. More than four in five patients visiting hospital thought there are always enough doctors and nurses on duty (about five per cent more than in 2000) although more could have been done to ensure patients had named nurses. Outpatients spent more time with doctors and nurses than in 2000, but appointments still rarely ran to time. More than four in five patients undergoing first treatment had trust in the doctors and nurses who cared for them. Trust and confidence in the doctor seen at the most recent outpatient visit was at a similar level, a marked improvement over the position in 2000.

14 More than nine patients in ten thought that hospital staff had done all they could to ease pain, although this was less likely among patients who had to tell staff about their pain, rather than have their pain level assessed by staff. A large majority of patients stated that they received support in dealing with distress and anxiety when needed, but a fifth of those in hospital and a quarter of those outside hospital who felt they needed help did not receive it. Patients who used them were enthusiastic for what they perceived as the benefits offered by complementary therapy services, but the extent to which they were informed about such services did not meet recent good practice guidance.

Most cancer patients were content with the support they received after discharge and as outpatients, but hospice provision and end of life choices could be enhanced

15 A large majority of cancer patients received information about what will happen after hospital. A fifth of patients reported that they did not receive printed information, and for a fifth of patients, home circumstances were not fully taken into account in arranging discharge. Most patients were well informed and knew what to expect when leaving hospital. Patients were satisfied with the information provided they received it.

16 After leaving hospital, three quarters of patients got the help they needed from the NHS and thought it met patients' needs very well. Pain relief after leaving hospital generally met patients' needs but patients frequently experienced overwhelming tiredness and 12 per cent of patients experienced this while reporting that not enough was done to alleviate it. Most patients lacked access to advice about financial benefits to support them or their family during or after their illness, though many wanted it while information about support groups continued to be received by around 60 per cent of patients.

17 The Department of Health is substantially increasing funding for the development of specialist palliative care services to be delivered by multi-disciplinary teams in the community, but coverage by multi-disciplinary teams in the community is not even across regions of England. Hospices, while welcoming recent initiatives, felt that staff and other resources remain constraints and a wider range of services should be provided.

18 Many terminally ill cancer patients have strong preferences about how they wish to spend their final days. Research shows that cancer patients often do not die in their place of choice.

The patient experience differed across cancer types and English regions

19 Within the overall results of our survey, we found noticeable and statistically significant differences between some groups of cancer patients after adjusting for possible other influences, (Appendix 3):

Cancer types

20 Responses from patients with breast and prostate cancers were more likely to differ from other cancers in survey responses to particular questions. Breast cancer patients were more positive than others in respect of the provision of information at diagnosis and on discharge from hospital, and in the rapidity of referral from GP to specialist where only three out of ten patients waited more than two weeks.

21 In the NAO survey, after excluding purely factual questions, we looked at the remaining 80 questions which made judgements about the quality of care provided. Patients with prostate cancer gave less positive responses than patients with other cancer types for 54 of these questions, and gave the most positive response to only 8 of the questions. Differences were particularly noticeable in the survey responses shown in **Figure 1**. These variations were also seen in 2000. Since 2000 the percentage of positive responses has generally improved for all cancers but more strongly for cancers other than prostate, leading in some areas of the patient experience to a widening gap in responses between patients with prostate cancer and those with other cancers.

22 More detailed statistical analysis (Appendix 3) strongly suggests that negative experiences of prostate patients persist even after allowing for regional, gender and age effects. The National Institute for Clinical Excellence issued Improving Outcomes Guidance on urological cancers in 2002, later than for other major cancers. The Department told us that this may explain partly why responses from prostate cancer patients are less positive.

1 Prostate cancer patients responded less positively than patients with other cancers

| | 2000 % | | 2004 % | |
|---|-------------------------------|-----------------------------|-------------------------------|-----------------------------|
| | Patients with prostate cancer | Patients with other cancers | Patients with prostate cancer | Patients with other cancers |
| Waited more than two weeks from referral by GP to be seen by specialist | 72 | 49 | 68 | 37 |
| Not discussed the side effects of treatment | 19 | 15 | 11 | 6 |
| Not discussed how treatment had gone | 14 | 8 | 13 | 5 |
| Would have preferred more information about how treatment had gone | 21 | 18 | 20 | 13 |
| Fully understood explanation of how treatment had gone | 67 | 76 | 70 | 81 |
| Have a named nurse in charge of care | 43 | 56 | 50 | 61 |
| Home situation not taken into account when discharged from hospital | 21 | 14 | 13 | 9 |
| Given information about support or self-help groups | 36 | 66 | 34 | 64 |
| Outpatient appointment cancelled one or more times | 17 | 13 | 19 | 11 |

Geographical variations

23 Our geographical analysis was based on the boundaries of the four Regional Directorates of Health and Social Care: London, the South, the Midlands and East, and the North. At this high level, differences are statistically significant. Taking the 80 questions referred to in paragraph 21, patients from the London region gave less positive responses than patients from other regions for 62 of these questions, and gave the most positive response to only eight of the questions. Differences were particularly noticeable in a range of survey questions in relation to Community and Hospital services, and the interface between them, detailed in Appendix 3. Further analysis strongly indicates that the less positive experience of London cancer patients in these questions persists even after allowing for cancer type, gender and age differences (see Appendix 3).

24 Although London patients recorded a less positive qualitative experience of care, our previous report, *Tackling Cancer: Saving More Lives*,⁵ did not show that cancer patients in London have worse survival and mortality rates than other parts of England.

Black and minority ethnic groups

25 Our survey had limited representation of black and minority ethnic patients, with only some 120 respondents (2.8 per cent of all respondents – roughly the same as in the 2000 survey). Around half of these respondents did not have English as a first language, which limited our ability to make observations in this area. However, black and minority ethnic groups have been shown by past research to have particular difficulties as cancer patients (and in dealings with the NHS generally). Reduced cultural sensitivity – such as provision for religious beliefs – and communications issues are more prevalent for minority ethnic cancer patients, who were less likely to understand their diagnosis and treatment options. Black and minority ethnic groups are less likely to be referred to, or choose to go to, hospice cancer services than other groups in society.

Deprivation

26 We divided the respondents to our survey into four groups of patients (using their postcode), from deprived to affluent, using the Index of Multiple Deprivation. Differences between the groups were very small for almost every question in the survey and there was no consistent statistically significant pattern of the most deprived group having more negative responses to survey questions than other groups. In other words they did not have a more negative perception of the service that they received from the NHS than more affluent patients.

Adverse experiences

27 We looked to see if the more negative experiences were concentrated within a particular group of patients, (Appendix 3). We focused on the eight questions where our survey showed that approximately one fifth of respondents had given less positive responses. This was to see if negative responses were the result of a particular group of patients registering across-the-board negative responses. The results indicate that this is not the case. Only two respondents gave a negative response to all eight questions. However, some groups were over-represented among those giving multiple negative responses: patients from London, and those with prostate and bowel cancer.



RECOMMENDATIONS

a Many of the ways of achieving the improvements to enhance the patient experience are already set out in guidance from the National Institute for Clinical Excellence. Cancer Networks have recently developed action plans to implement the guidance – Strategic Health Authorities (SHAs) should confirm that these action plans will deliver the necessary improvements over the next three years. The Cancer Action Team should collate information from all 34 Network action plans to assess the extent to which the guidance will be fully implemented within the next three years. Comparative information should be fed back to networks and SHAs.

b User involvement in cancer services is supported by Partnership Groups (a forum for bringing together health professionals and service users), reflecting good practice guidance from the National Institute for Clinical Excellence and the Manual of Cancer Services. SHAs should satisfy themselves through the performance management of Cancer Network action plans that these Partnership Groups are adequately resourced.

c Regular good quality surveys of patient experience should be undertaken at a local level to help drive up the quality of care. The questionnaire developed for the National Cancer Patient Survey and used with amendments in the current NAO study, should be adapted as a template, and piloted for use on a regular basis by Cancer Networks, NHS Trusts and individual cancer teams. This will avoid duplication of effort and provide consistency across areas for comparability purposes. Issues identified as weaknesses should be surveyed using more detailed modules of the full survey. The findings of such assessments should inform commissioning.

d Prostate cancer patients in the survey conducted for this study reported a generally poorer experience of care than patients with other common cancers. Particular attention should therefore be given by Cancer Networks to implementing the guidance on urological cancers, of which prostate cancer is one, not least by providing all patients with access to a urological cancer nurse specialist, in a way that is measurable and allows for comparisons with other areas.



e The worse experience of care reported by patients in London should be investigated further. The National Cancer Director should ensure that the Strategic Health Authorities and Cancer Networks in London are aware of this and that appropriate remedial action is taken.

f The work undertaken through the Cancer Services Collaborative 'Improvement Partnership' to develop Network-wide approaches to information delivery should be extended to all Cancer Networks and all tumour types as soon as is reasonably possible.

g The advanced communication skills programme currently being developed by the Cancer Action Team and the NHSU (the corporate university for the NHS), intended to improve communication between health professionals and cancer patients, their families and carers, should be rolled out to healthcare professionals across England as soon as possible.

h The Cancer Action Team should develop a standardised approach to the assessment of patients' physical, psychological, social and spiritual needs for use by all health professionals caring for patients with cancer. Services to meet patients' needs should be established in line with NICE guidance.