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**DEPARTMENT OF HEALTH**

# Tackling Cancer: Improving the Patient Journey

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**21 February 2005**

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### Note about tables and graphics in this report

- The sources of the data in all tables and graphics used in this report are the NHS National Cancer Patient Survey of 2000 and the NAO National Cancer Patient Survey of 2004, unless otherwise stated.
- All the changes in the level of responses for individual questions between the 2000 and 2004 respondents, or between sub-groups of respondents, are statistically significant to a confidence level of at least 95 per cent when subjected to chi-squared testing, unless otherwise stated.
- All patient survey data in this report from the surveys in 2000 and 2004 is presented excluding respondents who responded that they "could not remember", unless otherwise stated.



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## SUMMARY



**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".<sup>1</sup> 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".<sup>2</sup> 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.<sup>3</sup> 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.<sup>4</sup> 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.

<sup>1</sup> The NHS Cancer Plan, A Plan for Investment: A Plan for Reform, Department of Health (2000).

<sup>2</sup> Foreword by the Prime Minister, The NHS Improvement Plan, HM Government.

<sup>3</sup> 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.

<sup>4</sup> 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*,<sup>5</sup> 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.

## PART ONE

Cancer patients were broadly positive about their experience with GPs, the speed of diagnosis and how they were informed they have cancer, but some groups of cancer patients had better experiences than others



## Patients' experiences prior to diagnosis were broadly positive, but less so for those with bowel cancer and for those in London

Patients were broadly satisfied with the quality of care provided by their GP prior to diagnosis

**1.1** The proportions of people eventually diagnosed with cancer, who visited their GP before seeing a specialist, were virtually unchanged since 2000, **Figure 2**.

**1.2** Nearly two thirds of cancer patients said that level of satisfaction with GP care prior to diagnosis was very good (**Figure 3**), but within this there were some notable variations:

- 61 per cent of patients with bowel cancer thought that GP care was very good against 67 per cent of patients with other cancers. Research commissioned by the Department of Health should assist GPs in correctly identifying patients with symptoms suggestive of bowel cancer;
- In London, 57 per cent of patients thought care was very good against 67 per cent elsewhere (Figure 3); and
- As well as the older age groups being more likely to rate care as "very good", they were much less likely to rate it as "poor" or "very poor" (**Figure 4**).

"My GP was very thorough in checking the cause of my symptoms. If he had not been, my prostate cancer might not have come to light".

*Response to NAO patient survey*

"I had bowel cancer but my doctor thought my symptoms were nothing serious – I had to insist on a hospital appointment".

*Response to NAO patient survey*

"In cases with symptom complexities, particularly those with 'soft' symptoms such as [bowel] cancer, [the GPs reported] difficulties in identifying cancer patients, which can cause either inappropriate referrals or slow diagnosis".

*Report from NAO GP focus group*

### 2 Four patients in five visited their GP before diagnosis

Patients with breast cancer were less likely to have seen their GP, reflecting the use of the breast screening service.

	All patients %		2004 patients %	
	2000	2004	Patients with breast cancer	Patients with other cancers
Visited GP first	80	80	73	81
Did not visit GP	20	20	27	19

### 3 85 per cent of patients rated pre-diagnosis care by their GP as good or very good

Patients in London were twice as likely as the rest of England to rate care as poor or very poor (12 per cent versus 6 per cent).

	All patients %	London patients %	Patients from elsewhere %
Very good	65	57	67
Good	20	21	20
Fair	8	10	7
Poor	4	7	3
Very poor	3	5	3

### 4 The level of satisfaction with pre-diagnosis GP care increases with age

Younger people were less likely to be satisfied with GP care than older people.

	16-35 years %	36-50 years %	51-65 years %	66-80 years %	81 years or over %
Very good	50	59	63	69	71
Good	23	22	20	20	18
Fair	16	9	9	7	8
Poor	11	10	8	4	4
Very poor	2	3	4	2	2

**1.3** Of the 222 people who recorded that their GP care was "poor" or "very poor", 210 gave reasons for their rating. The most common cause for dissatisfaction was failure to diagnose symptoms by a GP, or failure to take symptoms seriously enough.

The speed with which patients were seen following referral had improved since 2000, and the proportion of patients perceiving their condition as worsening during the wait had fallen from over a quarter to a fifth

**1.4** People who may have cancer normally wish to get the uncertainty surrounding their condition cleared up as quickly as possible. The National Cancer Patient Survey in 2000 found that almost half of non-breast cancer patients were waiting longer than one month for their first specialist consultation and frequently perceived that their condition had worsened as a result.

**1.5** For people who first go to see their GP about symptoms (as opposed to referral to specialists via screening services or admission through accident and emergency), the Department of Health has a target that all patients with suspected cancer referred urgently by their GP should be seen by a specialist within two weeks. This target is now being achieved for 99 per cent of patients referred urgently by their GP. Our earlier report, *Tackling Cancer in England: Saving More Lives* HC 364, 2003-04,

estimated that approximately one third of cancer patients might not be referred urgently. Our survey indicates that the actual figure may be higher than this (**Figure 5**), since over 40 per cent of patients had waited more than two weeks. However, the situation had improved markedly compared with 2000. Figure 4 also shows that fewer patients waited over a month between GP referral and being seen by a specialist than in 2000.

**1.6** As cancer progresses with time, symptoms might or might not be apparent to patients. The patient's own perception of their condition is an important element in their psychological well-being. Alongside the reduction in waiting times to see a specialist, the proportion of patients reporting a worsening of their symptoms during the time they were waiting for a hospital appointment fell from 26 per cent to 20 per cent (**Figure 6**).

**1.7** The situation was worst for bowel cancer patients, reflecting in part the difficulty that GPs, among others, had in separating bowel cancer symptoms from those of other conditions, with resulting longer waits for diagnosis. The figure of 30 per cent who saw their condition worsen was nonetheless a reduction from 37 per cent in 2000. Patients of all types in London reported greater deterioration in their condition despite only waiting marginally longer than in other parts of the country. Patients in many parts of London, however, have survival and mortality rates that compare favourably with other parts of the country.

## 5 Fewer patients waited more than two weeks from referral by GP before seeing a specialist in 2004

Patients with breast and lung cancer were far more likely to be seen faster than patients with bowel and prostate cancer, but improvements have been seen in all four cancers.

	All patients %		Breast cancer patients %		Lung cancer patients %		Bowel cancer patients %		Prostate cancer patients %	
	2000	2004	2000	2004	2000	2004	2000	2004	2000	2004
Seen within 2 weeks	46	58	62	70	49	68	36	51	28	32
Seen in more than 2 weeks but less than 1 month	24	22	24	20	24	21	25	23	22	29
Seen between 1 and 3 months	19	15	10	8	17	8	24	20	32	27
Seen in more than 3 months	11	5	4	2	10	3	15	6	18	12

## 6 Fewer patients reported their condition worsening while waiting to see a specialist

Patients of all types in London and, in particular, patients with bowel cancer nationally were much more likely to feel their condition worsened while waiting to see a specialist.

	All patients %		Bowel cancer patients %		Patients with other cancers %		2004 Regional variations %	
	2000	2004	2000	2004	2000	2004	London	Non-London
Condition worsened	26	20	37	30	20	16	27	19
Proportion of patients waiting between 2 weeks and 1 month to be seen by a specialist	24	22	25	23	23	22	23	22
Proportion of patients waiting more than 1 month	30	15	39	27	26	16	22	19

**1.8** Our data for 2004 show that women as a whole were seen more quickly than men after referral. Patients with breast cancer were seen quickest and patients with prostate cancer the slowest. However, for the cancers affecting both sexes, women with bowel cancer waited longer to be seen by a specialist than men with the disease, **Figure 7**. No significant differences in times to referral were observed between men and women with lung cancer. Across all cancers, women were less likely to report a deterioration in their condition while waiting than men – reflecting in part that women with breast cancer were seen most quickly, while prostate cancer patients were seen least quickly. For bowel and lung cancers, however, the opposite was true and women were more likely to report a deterioration than men. These findings are similar to those in 2000, though women lung cancer patients in 2000 were seen less quickly than men but in 2004 were seen more quickly.

## 7 Women continued to be more likely to report a worsening in their condition for bowel and lung cancers in 2004

	Patients with bowel cancer		Patients with lung cancer	
	Men	Women	Men	Women
<b>Proportion waiting longer than 1 month to be seen by specialist:</b>				
2000	35	39	25	28
2004	26	29	11*	10*
<b>Proportion who reported condition worsening:</b>				
2000	35	39	29	30
2004	28	32	21	24

### NOTE

\* Difference between men and women not statistically significant.

More information about diagnosis of cancer was communicated more effectively and with greater sensitivity than in 2000, but these aspects continued to be a common cause of patient complaints

More cancer patients understood the explanation given by clinicians of what was wrong with them and approved of the length of consultations but few were given a record

**1.9** In the NHS National Cancer Patient Survey in 2000 patients generally reported positively on the manner and length of the consultation during which they were given their diagnosis, but there were considerable gaps in the provision of written communication.

**1.10** Figure 8 shows that there were high levels of satisfaction with the manner of consultation at the point of diagnosis. The proportions were slight improvements on the situation in 2000.

8	As in 2000, patients were largely satisfied with what they were told at the time of diagnosis, and the opportunities to seek clarification	
	2000	2004
Patient understood the explanation of what was wrong:		
Completely understood	84	86
Understood some	14	14
Didn't understand	2	0
Patients' questions answered understandably:		
Yes	*	96
No	*	2
No chance to ask	*	2
Time taken for consultation:		
About right	93	93
Not right	7	7
NOTE		
* Not asked in 2000.		

**1.11** The overwhelming majority of patients (93 per cent) felt that the amount of time spent discussing the diagnosis was right, though there were small but statistically significant differences between tumour types (Figure 9). The length of time spent on the consultation also varied between tumour types, being shortest for prostate cancer patients. Seventy four per cent of patients who said their consultation was too short spent less than ten minutes with the specialist, compared with 18 per cent of all patients.

**1.12** Patients generally fully understood the purpose of tests and options for treatment. Between 2000 and 2004, full understanding of the purpose of tests increased from 81 per cent to 86 per cent, while full understanding of treatments remained at 83 per cent.

**1.13** Under new guidance from the National Institute for Clinical Excellence published at the time of our patient survey, in March 2004,<sup>6</sup> it is now recommended that patients should be offered a record of the discussion. In our survey, which provides a snapshot of the situation at the time that the guidance was introduced, 90 per cent of patients in the survey were not given a written or audio record.

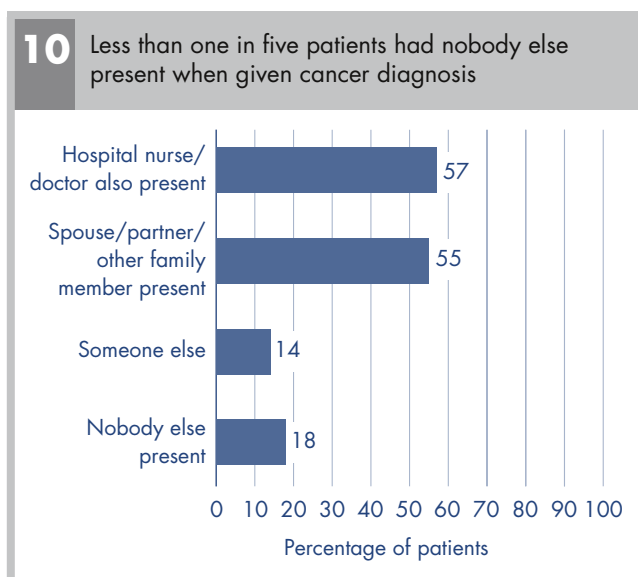
9	There were statistically significant variations in consultation times and satisfaction levels between cancer types			
	Breast %	Bowel %	Lung %	Prostate %
Time spent was about right:				
Yes	93	94	95	91
No	7	6	5	9
Time spent in consultation:				
Less than 10 minutes	16	18	15	30
10 – 29 minutes	58	59	60	59
30 – 59 minutes	24	20	21	10
One hour or more	2	3	4	1

6 Improving Supportive and Palliative Care for Adults. National Institute for Clinical Excellence (2004).

## Most patients considered they were told bad news with suitable sensitivity

**1.14** Patients reported largely positively about the sensitivity with which they were told bad news and the ease of communicating with the person telling them. As in 2000, 94 per cent of patients thought that the diagnosis was given with sufficient sensitivity and care. The same proportion thought that the person giving the diagnosis was easy to talk to. In 2004, ten per cent of patients were told by a nurse compared with six per cent in 2000. This was likely to indicate the increased use of trained Clinical Nurse Specialists to break bad news.

**1.15** National Institute for Clinical Excellence guidance recommends that a cancer diagnosis should be communicated "ideally in the company of a close relative or friend (if the patient so wishes) and in the presence of a specialist nurse where possible". **Figure 10** indicates that



less than a fifth of patients were on their own when told they had cancer though only 55 per cent were with family or a friend as recommended by the guidance.

**1.16** Further analysis, **Figure 11**, showed that nearly one half of those with a spouse/partner or other family member present would have liked another such person to be present. Amongst those who did not have such a person present, around 30 per cent would have liked to have. However, among those who had nobody present nearly four fifths would not have wanted anyone else present.

Patients who received it understood the printed information about their diagnosis, and it was given out more often than in 2000, but four in ten cancer patients did not receive it

**1.17** Substantially more patients received written information at the time of their diagnosis about their cancer and treatment in 2004 than in 2000, **Figure 12 overleaf**. This information was understood completely by 84 per cent of those who received it and to some extent by the rest.

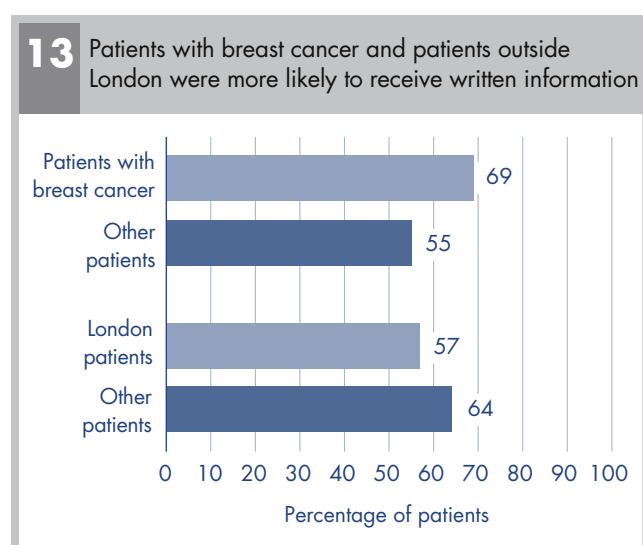
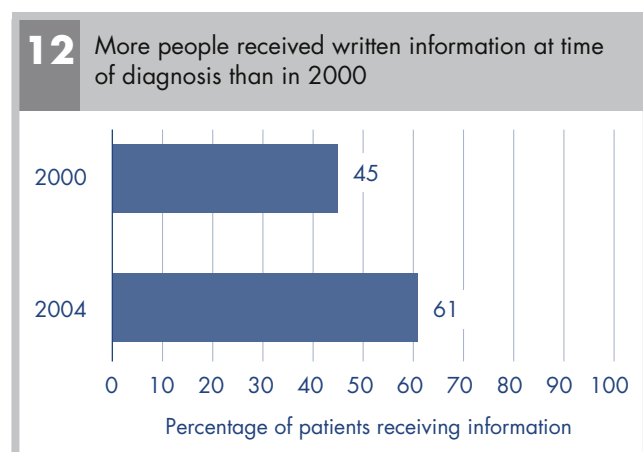
**1.18** In our survey of Cancer Networks we asked them what they had done to ensure that high quality information is available to patients. Thirty one out of the 34 Networks completing our survey had taken some action in this area, with 22 collecting and disseminating good practice to those organisations in contact with patients, seven Networks issuing guidance to trusts, and eight Networks monitoring Trusts' progress in this area. Three Network teams had not yet taken any action. There are more than 20 information managers now in post among Cancer Networks.

## 11 Patients with a family member present at diagnosis would have often preferred more, while those who came on their own generally preferred this arrangement

Also present besides person giving diagnosis:	Number of patients in each category	Percentage of patients who would also have liked the following present:			
		Spouse/partner/other family member	Nurse	Doctor	Nobody else
Spouse/partner/other family member	2524	45	7	8	40
Hospital nurse	2040	30	10	8	52
Nobody else	716	19	1	2	78
Hospital doctor	656	31	10	13	46
Other	607	41	10	10	39

**1.19** Hospitals increasingly hand out information packs with a range of leaflets about the tumour type and what happens next. Much useful information related to cancer, possible treatments and services which are available, is produced by the voluntary sector. This information is always free to patients at the point of treatment, even if hospitals have to pay for it themselves. The NHS Cancer Services Collaborative 'Improvement Partnership' is working with Cancer Networks to encourage Trusts to map information needs along their care pathways and to make use of existing information resources and templates rather than re-inventing the wheel. The information requirements for fully informing patients which can be revealed by such a mapping exercise, even for just the early stages of the patient's care pathway, are illustrated by Appendix 4.

**1.20** There were variations in the provision of written material between cancer types and geographical areas, **Figure 13**. Although there are more sources of information about breast cancer, full information about all major cancers is available to hospitals from a range of sources.



## Information is not always culturally sensitive

**1.21** It is recognised that black and minority ethnic patients, especially when English is not a first language, have particular problems with communication issues around diagnosis. The National Cancer Patient Survey in 2000 identified that minority ethnic patients, especially South Asian patients, were less likely to understand their diagnosis and treatment options (also reflected among the small black and minority ethnic portion of 2004 respondents).

**1.22** The provision of written information in languages other than English can be a problem for many hospitals. Hospitals outside of large urban areas told us that they did not hold information about cancer treatment in their Trust in other languages as a matter of course, as demand was intermittent due to very low numbers of non-English speaking patients. When such information was necessary, ad hoc solutions were sought. Fifteen Cancer Networks told us that they were collecting and disseminating good practice to ensure that patient information is culturally sensitive. However, ten networks said that they had taken no action to ensure that patient information met the needs of ethnic minorities.

**1.23** Examples can be found in some hospitals of an impressive range of non-English written, audio and visual aids for non-English speakers. We visited the Christie Hospital in Manchester, which had carried out an investigation into the information needs of black and minority ethnic patients in 2002. They found that these patients were being disadvantaged by the lack of information in languages other than English. As a result they produced a booklet for black and minority ethnic patients in 2003 listing sources of information and support in the local community, supported by a range of other materials for non-English speakers, as illustrated opposite.

**1.24** Since 2003, cancer information charity CancerBACUP has operated an interpreting service, Cancer In Your Language, on its helpline. Speakers of the 12 commonest community languages, covering approximately two thirds of British ethnic minority communities, can dial direct to an interpreter who links with a cancer information nurse specialist; the helpline can also contact interpreters for speakers of most other languages spoken in England. This complements the outreach work undertaken with people from South Asian, Turkish, Chinese and African-Caribbean communities and is funded by a grant from the Big Lottery Fund (formerly the New Opportunities Fund).



## PART TWO

Cancer patients' experience of care given by hospitals improved between 2000 and 2004 but there were still gaps in supportive and palliative care



## Patients and their carers were more involved in their care and treatment than in 2000, but few are told how to complain

**2.1** When patients enter hospital they rightly expect to be treated with dignity and respect and to be involved in decisions about their treatment and care. In 2000, within an overall picture of generally high satisfaction with aspects of their hospital care, roughly one in five patients raised issues around treatment with respect, trust in all nurses, numbers of staff on duty and whether everything had been done to relieve pain. We investigated whether these issues had been addressed in the period since 2000.

Since 2000 hospitals had become better at communicating with patients about their condition, treatments and tests

**2.2** Patients need to be able to understand their condition and treatment options if they are to be fully engaged in decisions about their care. We found in 2004 (**Figure 14**) that only a tiny proportion of patients had difficulty in understanding doctors' explanations of their condition, tests or treatment. A third of patients said they found the explanations "fairly easy", rather than "very easy", to understand. Eighty eight per cent of 2004 patients never felt that doctors and nurses were deliberately withholding information. Two per cent felt that it happened once, and the remainder more than once. These figures were unchanged from 2000.

**2.3** Patients are understandably concerned to ask questions and they expect straight and clear answers. The replies they received were understood more often in 2004 than in 2000, **Figure 15**. Levels of understanding of answers given by doctors and nurses were similar, at around 85 per cent in both cases. This nevertheless leaves a small minority of patients who did not feel they had clear replies to their questions.

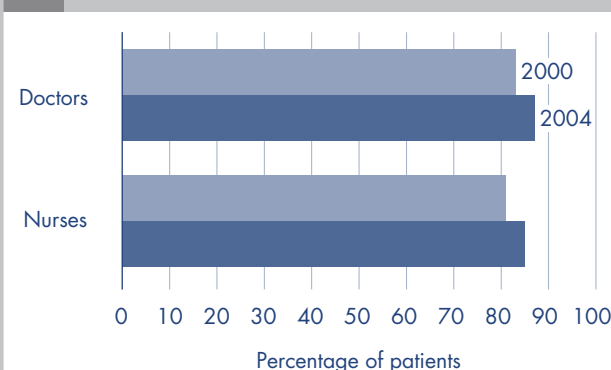
"They told me when my treatment was going to be, and they gave me a schedule of how the treatment would be organised, and as a result I felt confident, knowing what they would be doing at which point in time".

*Focus group patient*

### 14 More patients found explanations of what was wrong with them easy to understand in 2004 than in 2000

	2000 %	2004 %
Explanation very easy to understand	62	68
Explanation fairly easy to understand	33	30
Explanation not easy to understand	5	2

### 15 The large majority of patients understood answers to questions by doctors and nurses all or most of the time

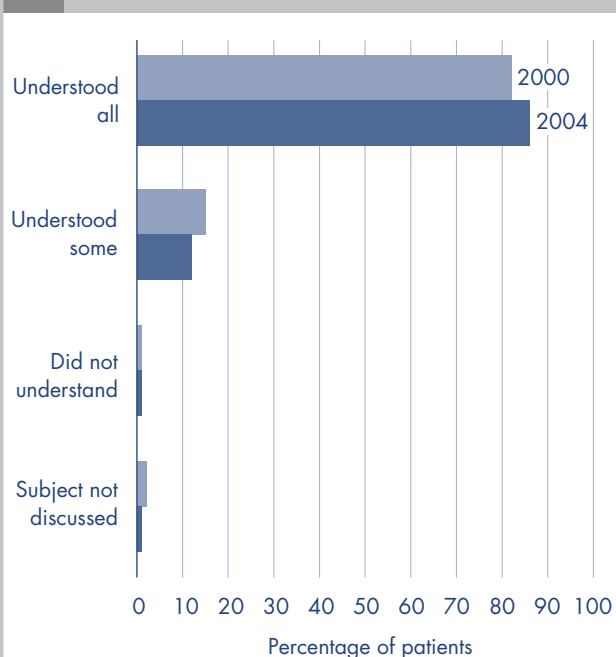


**2.4** Nearly all patients who wished to discuss it reported that they understood the purpose of their treatment, but of these 12 per cent understood it only partly, (**Figure 16**).

Patients' understanding of side effects had improved significantly since 2000, but a fifth had less than a full understanding or the issue was not discussed

**2.5** Hospital staff have an important role to play in warning patients of the potential side effects of their treatment, which can be considerable. The position had improved significantly since 2000. More than three quarters (76 per cent) of patients had discussed and fully understood the explanations about side effects in 2004, compared to less than two thirds (63 per cent) in 2000, (**Figure 17**). The proportion that had an unsatisfactory discussion or no discussion fell from 30 per cent to under 20 per cent.

**16** Nearly nine out of ten patients fully understood the purpose of the treatment



**NOTE**

Excludes patients who did not wish to discuss the purpose of treatment.

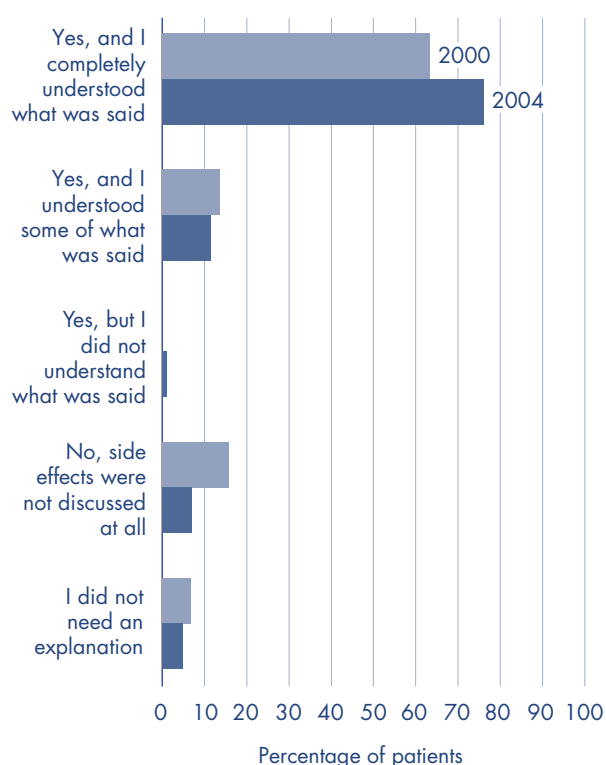
**2.6** There were variations between cancer types. Compared with patients with other cancers, patients with prostate cancer were almost twice as likely not to be informed about side effects (11 per cent versus six per cent), despite the fact that some prostate treatments can have serious and long-lasting side effects for patients.

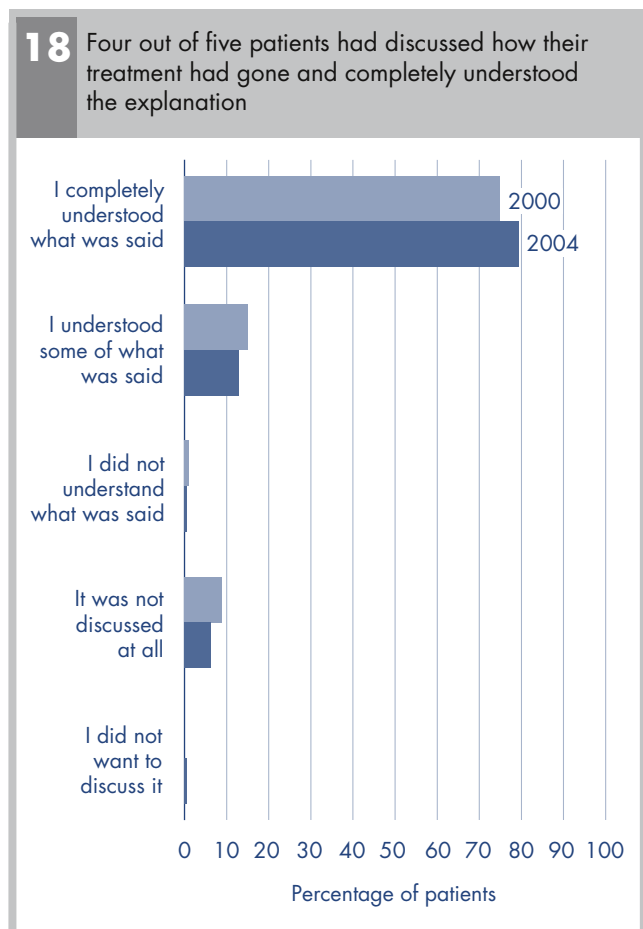
Discussions after treatment were broadly satisfactory but understanding was not complete for about 20 per cent of patients

**2.7** Nearly 80 per cent of patients in our survey reported that they completely understood the discussion about how well their treatment had gone, (**Figure 18**), and slightly more felt that they were told the right amount about how their treatment had gone, (**Figure 19**). Both of these responses showed improvement compared with 2000.

**17** Three quarters of patients were now given completely understandable explanations about side effects

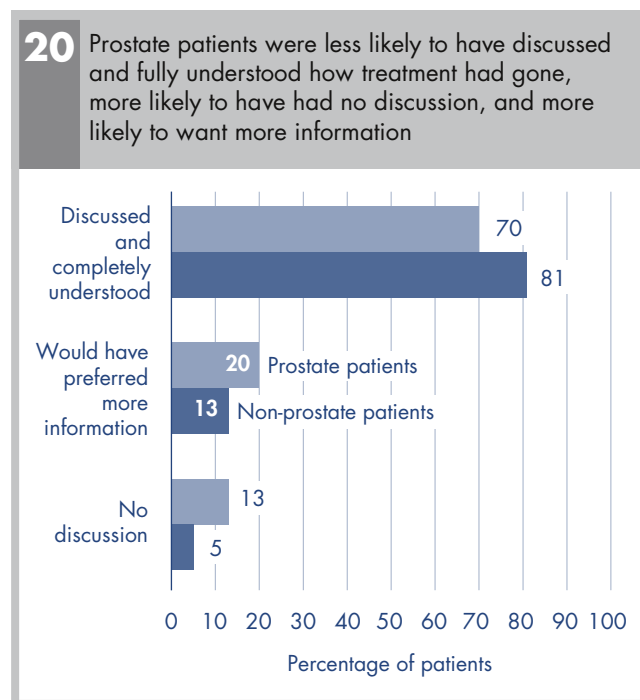
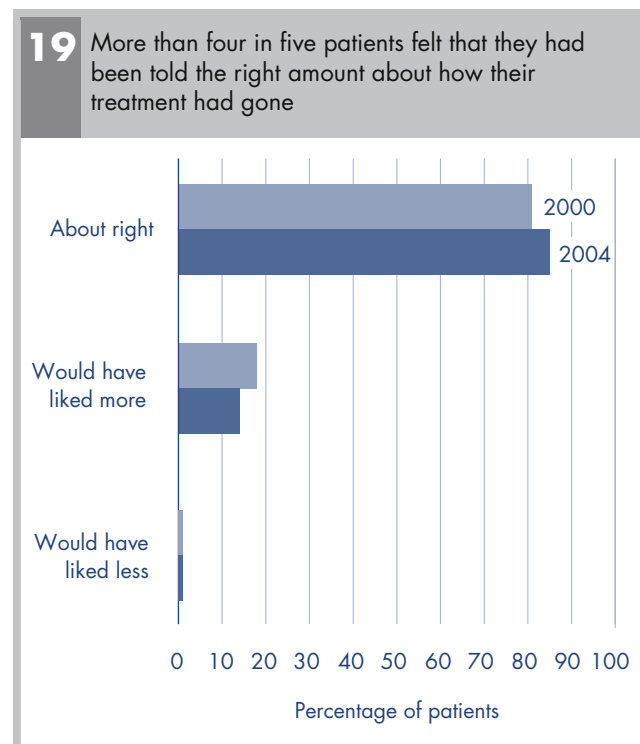
The proportion of patients who had not discussed potential side effects at all fell from 16 to 7 per cent.



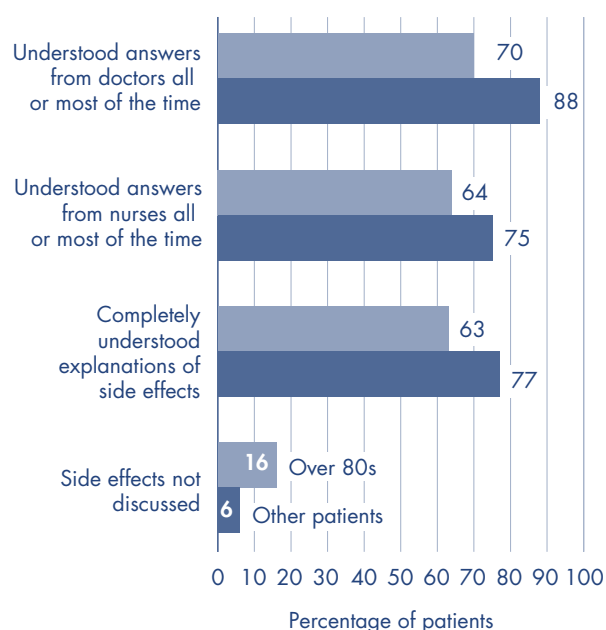


**2.8** As with the pre-treatment discussions above, patients with prostate cancer gave noticeably different answers to these questions (**Figure 20**). Compared to other cancer patients, patients with prostate cancer were less likely to have understood what they were told, were more than twice as likely to have had no discussion, and nearly twice as likely to have an unmet need for information.

**2.9** Patients over the age of 80, consisting of around 250 respondents, gave less positive responses to a number of questions around discussions of their condition and treatment (**Figure 21 overleaf**). Although they did not have any particular difficulty with initial explanations received, they were more likely to encounter difficulties when asking follow-up questions. They were also less likely to be well informed about side effects, despite the fact that this group might be particularly vulnerable because of other conditions.



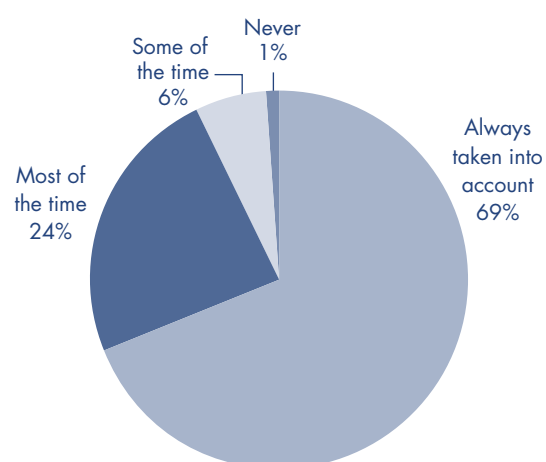
## 21 People over 80 had particular communications issues in a number of areas



Most patients felt that they, and their families, were involved in decisions about their care, though with some concerns on the part of patients with prostate cancer

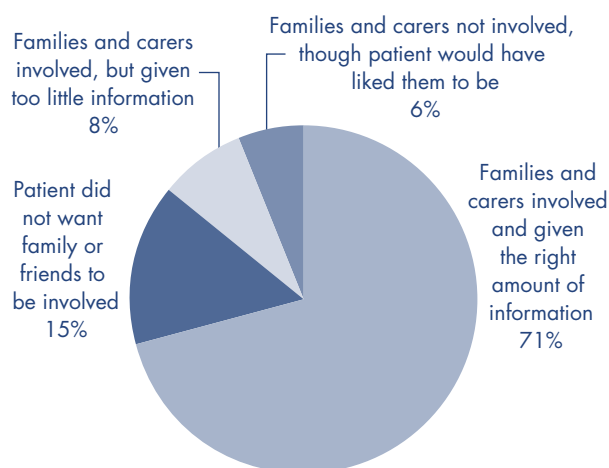
**2.10** Eighty five per cent of patients were involved in decision making as much as they wanted in 2004. This represented a small fall since 2000 (89 per cent). One possible explanation could be the increasing expectations of patients. Nearly 70 per cent of patients felt their views were always taken into account, **Figure 22**. More than 70 per cent of patients reported that family and friends were involved as much as desired (**see Figure 23**) – a slight increase on 69 per cent in 2000. Patients with breast and prostate cancer were less likely to want the involvement of family and friends (20 and 17 per cent respectively, compared with 11 per cent of bowel cancer patients and eight per cent of lung cancer patients).

## 22 Seven out of ten patients thought that their views about treatment were always taken into account



## 23 Most patients gave positive responses about the level of involvement of families and carers in treatment decisions

15 per cent of patients did not want family or friends to be involved.



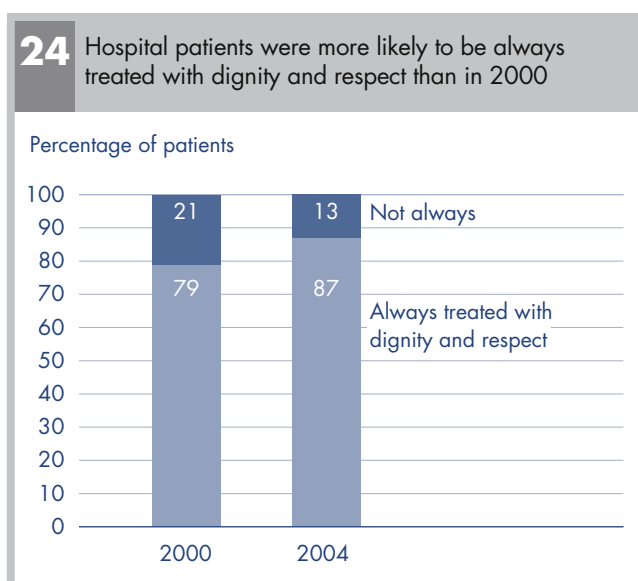
### NOTE

This chart excludes those without family or friends who could be involved.

Most patients felt that they were being treated with respect and dignity and with sensitivity, but few were told how to complain

Most patients are always treated with respect and dignity

**2.11** In 2000, four out of five patients considered that they had always been treated with respect and dignity by hospital staff. In 2004 the proportion had increased to nearly nine in ten patients treated in hospital, **Figure 24**. For the most recent visit to an outpatient doctor the proportion treated with respect and dignity in 2000 was higher than 99 per cent. In 2004 the question gave patients the option of reporting that they were treated with respect and dignity "completely" (96 per cent) or "to some extent" (three per cent).



Patients got privacy during their examination but some would have liked more during discussion of their condition

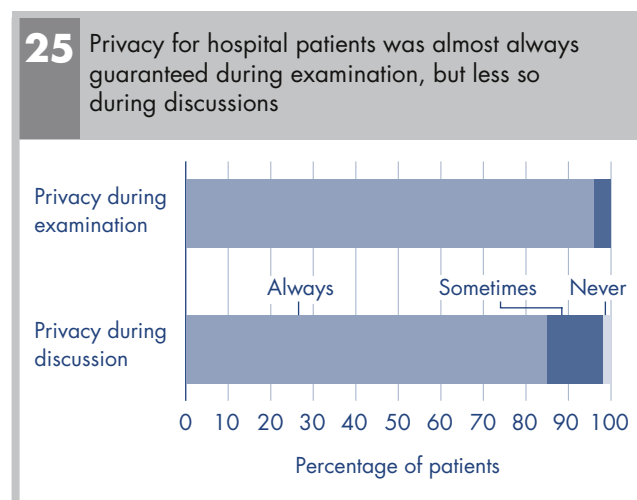
**2.12** It is very important for patients to have privacy during their examination and during discussions. Patients in hospital almost always felt they had enough privacy during their examination, but 15 per cent said they would have preferred more privacy when discussing their condition, **Figure 25**. Both of these findings were slight improvements on 2000.

"A curtain round a bed on a ward does not give any form of sound-proofing".

*Comment on patient survey*

Patients were unlikely to be told how to complain and some who did were not satisfied with the result

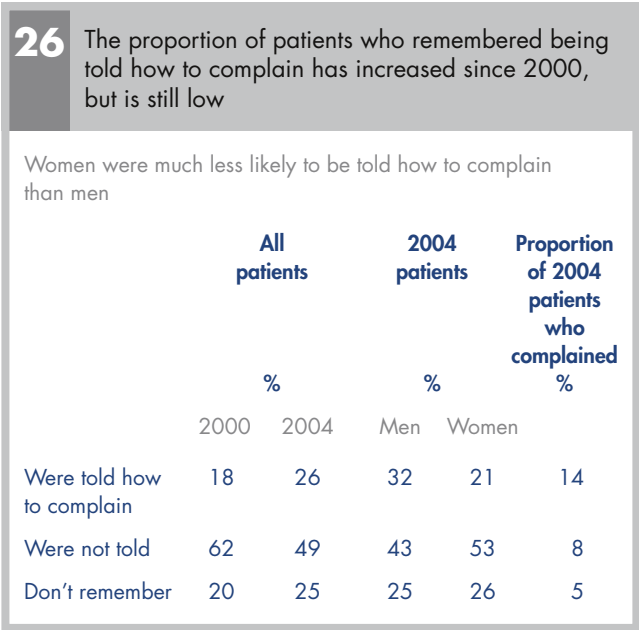
**2.13** A clear and accessible process through which patients can complain or comment on the quality of care they have received is an essential part of any modern health system.<sup>7</sup> NHS organisations and primary care practitioners are required to publicise their local complaints handling process. This could be as a stand alone leaflet (or any other media) on complaints or as part of a general patient information leaflet. In our Cancer Patient Survey, we asked patients if they had been told how to complain about the care that they received, and, if they had complained whether their complaint was satisfactorily addressed.



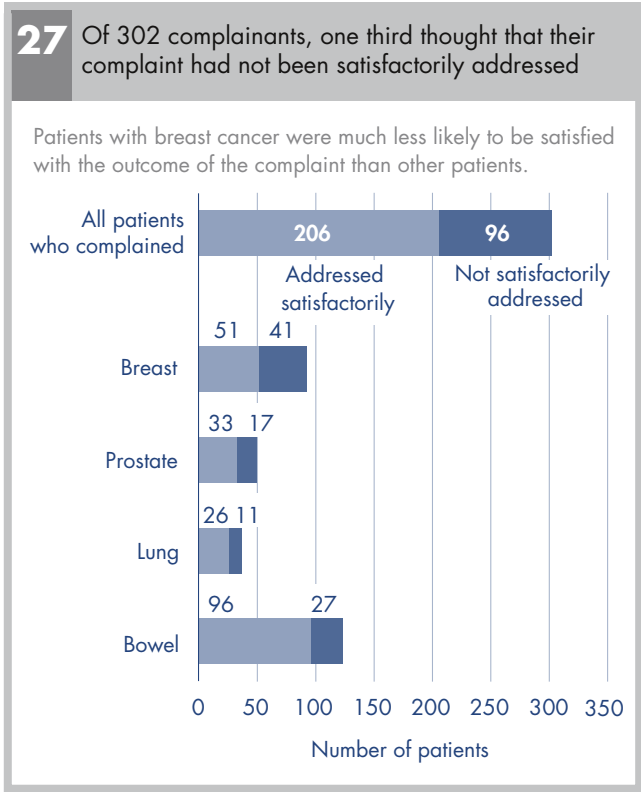
7 Building a safer NHS for patients. Department of Health (2001).

**2.14** Only about one quarter of cancer patients were given information about how to complain in 2004 (a further one quarter did not remember whether or not they had been told how complain), **Figure 26**. In 2000 only 18 per cent of patients reported that they had been told how to complain, with a further 20 per cent being unable to remember. Ninety two per cent of those who were told how to complain said they were always treated with dignity and respect by staff in hospital, while only 83 per cent of those who were not told how to complain said the same.

**2.15** As in 2000, more men than women reported that they had been told how to complain (32 per cent versus 21 per cent). The difference was particularly marked for bowel cancer (men 47 per cent versus women 33 per cent). Across all cancers, men were more likely to have complained than women (11 per cent versus seven per cent). Patients who were told how to complain were much more likely to complain than those who were not (14 versus eight per cent).



**2.16** Out of some 3,400 respondents who reported whether or not they had complained, 302 (nine per cent) said yes. One third reported that their complaint had not been dealt with satisfactorily (**Figure 27**). Patients who had been told how to complain were, however, much more likely to report that their complaint had been satisfactorily addressed (**Figure 28**).



**2.17** Of the 302 patients who complained, 203 provided us with written comments. Of these, some 15 per cent were about issues not directly related to clinical care, such as catering standards. Of the remainder, three groups of complaints were most common (and least likely to be satisfactorily resolved): rudeness of staff, poor quality inpatient care on wards and patients not being listened to during diagnosis. Since 1996-97, when current NHS surveys of this type started, these categories of complaint have consistently been among the most frequently occurring. The NHSU, the corporate university of the NHS, is developing and providing training in complaint handling and customer care. Progress is also being made through communication skills training for doctors and other health care professionals, based on research indicating that thorough training of this sort produces benefits for patients.<sup>8</sup> Most patients thought their complaint was satisfactorily addressed, though overall a third did not. Among breast cancer patients specifically, the proportion satisfied with the outcome of their complaint fell to half.

## Patients gave largely positive responses in respect of the care they received from doctors and nurses, but the level varies in a number of areas

Inpatients have better access to doctors and nurses than in 2000, although more could be done to ensure patients have named nurses

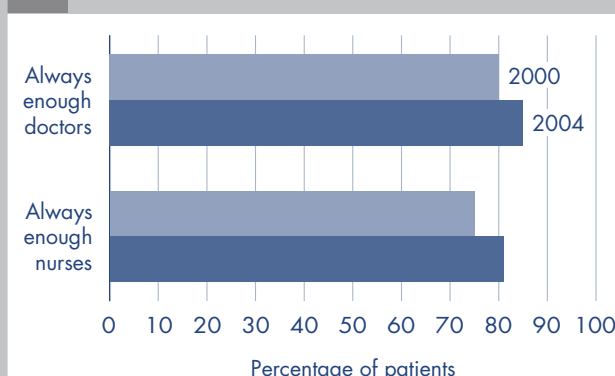
**2.18** In 2000, only about half of patients were placed in the care of a named nurse. There was a marked improvement by 2004 – some 60 per cent of patients were now in the care of a named nurse who would be in overall charge of their care and to whom they could turn for help or information, **Figure 29**. Patients in the North of England were more likely to have a named nurse, while prostate cancer patients were rather less likely than other cancer patients to have a named nurse. The lower number of Clinical Nurse Specialists for prostate cancer reflects the fact that guidance on urological cancers (including prostate) recommending their adoption has only existed for two years. The proportion of patients with a named doctor or surgeon, on the other hand, was 95 per cent in 2004, very slightly higher than 2000.

**2.19** It is important that there are enough members of hospital staff on duty. Again there were improvements between 2000 and 2004, **Figure 30**, and in 2004 85 per cent of patients felt there were always enough doctors on duty and 80 per cent felt the same about nurse staffing.

### 29 Six in ten patients had a named nurse in overall charge of their care

	All patients %		2004 patients %			
	2000	2004	Patients in the North	Patients elsewhere	Patients with prostate cancer	Patients with other cancers
Had a named nurse	54	60	64	57	50	61

### 30 More patients thought that there were enough doctors and nurses on duty in 2004 than in 2000

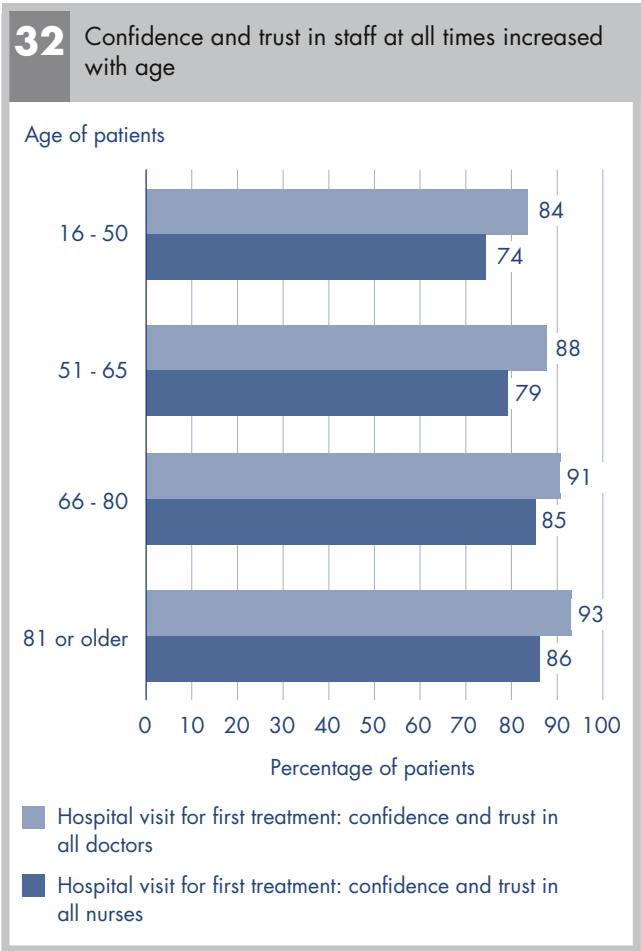


<sup>8</sup> For example: Jenkins and Fallowfield. Can communication skills training alter physicians' beliefs and behaviour in clinics? *Journal of Clinical Oncology* 2002; 20: 765-769.

Confidence and trust in doctors and nurses remained high

Patients had high confidence in doctors and nurses though with variation across regions and by age

**2.20** It is also very important that patients have confidence and trust in their doctors and nurses. **Figure 31** shows improvements from a high level in 2000. Trust and confidence increased with age, **Figure 32**, although a substantial majority of patients had confidence and trust, whatever their age.



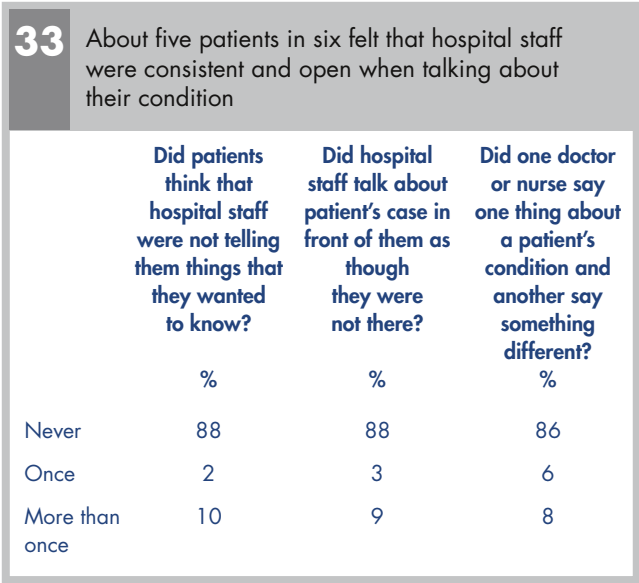
Most patients established a good relationship with healthcare staff

**2.21** The percentages of patients who gave positive responses about a range of questions relating to the way that information about their condition was communicated to them, **Figure 33**, were virtually the same as in 2000 at nearly 90 per cent. As in 2000, bowel cancer patients were most likely to report being talked about as though they were not there (17 per cent versus 11 per cent of other patients).

The needs of most patients for pain relief was met, but a minority remained under-supported

Two thirds of patients continued to experience pain at points during their treatment

**2.22** Pain is a common but by no means universal by-product of cancer and its treatment. Techniques increasingly exist to control a great deal of the pain caused by cancer and its treatment, but the degree to which pain is felt varies from person to person, and this makes pain management a demanding skill. In 2004, almost two thirds of patients were in pain while receiving hospital treatment, slightly lower than in 2000 (63 versus 65 per cent), **Figure 34**. The proportion of all patients suffering severe pain (14 per cent) in 2004 was a slight increase on 2000.



**2.23** The issue of most concern is whether as much as possible is done to minimise patients' pain. Patients said that staff were aware of their pain in almost all cases (just over four in every five patients had been asked). Fifteen per cent of patients in hospital reported in our survey that they did not think staff had done everything they could at all times to reduce pain, **Figure 35**. This was an improvement over the position in 2000, when 19 per cent of patients felt more could have been done. Within that figure, some groups were less satisfied with the level of support offered than others.

### Pain relief after leaving hospital generally met patients' needs

**2.24** About sixty per cent of cancer patients in our survey were in pain after leaving hospital, of whom most were in moderate or severe pain, **Figure 36**. A large majority of patients told us that they were given enough help to deal with their pain (**Figure 37 overleaf**), but patients with prostate cancer were twice as likely to say they were not as other patients (14 versus seven per cent of those in pain). This survey was not able to cover the issue of pain felt by patients in the last days of life.

**34** The proportion of patients in pain has fallen slightly since 2000, but the proportion in moderate and severe pain has increased slightly

In pain?	2000 %	2004 %
Yes	65	63
No	35	37
<b>Extent of pain</b>		
Severe	13	14
Moderate	35	37
Mild	15	11
Can't say	2	1
None	35	37
<b>Frequency of pain</b>		
All of the time	*	8
Some of the time	*	55
None of the time	*	37

NOTE

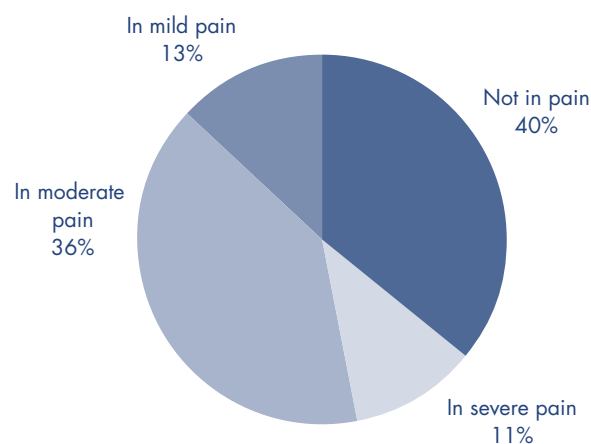
\* Not asked in 2000

**35** Five patients out of six thought that hospital staff had done all they could at all times to relieve pain

**Proportion of patients who thought that, in order to relieve pain, hospital staff did all they could, all of the time**

	Number of respondents	Proportion %
All patients	2,311	85
Patients in severe pain	507	73
Patients in moderate or mild pain	1,741	89
Patients who told staff about pain because staff asked	1,887	92
Patients who told staff about pain despite not being asked by staff	325	55

**36** Six out of ten patients were in pain to some degree after leaving hospital

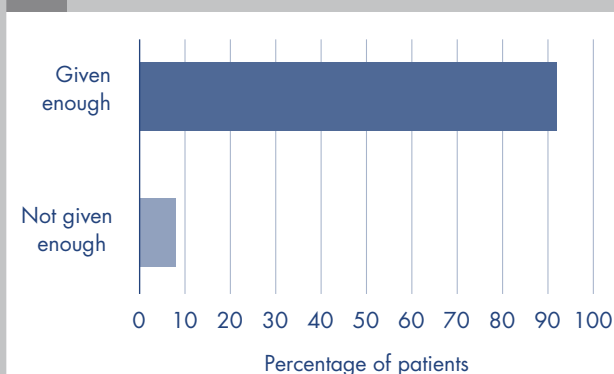


Most patients in need of help for stress and anxiety reported that they received such help, but a minority did not, both during hospital visits and after

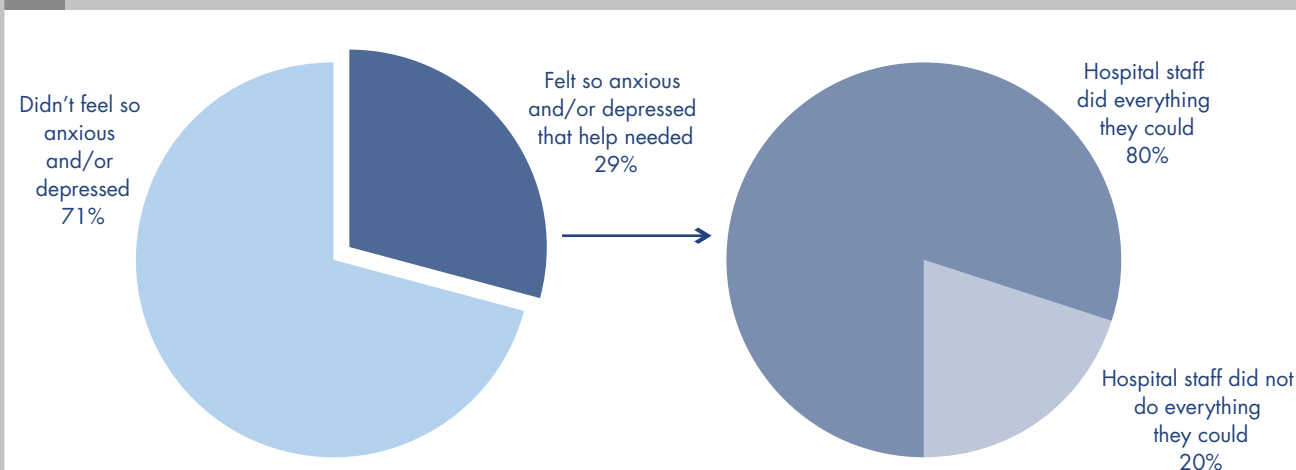
Though most cancer patients receiving first treatment for cancer stated that they received support in dealing with distress and anxiety if needed, a fifth did not, often because they were not asked or because they did not say they needed it if they were asked

**2.25** Psychological distress is common among patients following a diagnosis of cancer, and for some this will be severe enough to require intervention from specialists. In our survey three in ten patients undergoing first treatment for cancer (**Figure 38**) and one quarter of patients at the most recent outpatient visit had experienced anxiety and/or depression severe enough that they felt they needed help to cope. A fifth of affected cancer patients reported that they thought more could have been done to assist with their anxiety or depression – six per cent of all cancer patients who responded on this point.

**37** More than nine in ten patients felt that they were given enough medication or other help to deal with their pain



**38** One in three cancer patients felt so anxious or depressed that they needed help to cope, but one fifth of those reported that hospital staff did not do all they could



**2.26** A large majority of cancer patients who were asked about their psychological state were willing to tell staff, and in those cases almost all thought that hospital staff had done all they could to help them, **Figure 39**. However, one third of those who had to inform staff of their psychological distress without prompting reported that staff could have done more.

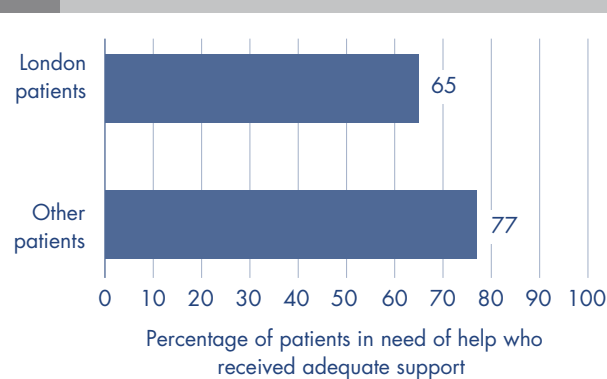
**39** If hospital staff did not ask patients about their psychological state, patients were much more likely to report that not enough was done for them

Staff aware of distress?	Numbers of patients	Patients thought hospital staff had done all they could %
Staff asked and patient told them	597	98
Patient told them but not asked	166	66
Staff asked but patient did not tell them	40	70
Staff did not ask, patient did not tell them	161	30

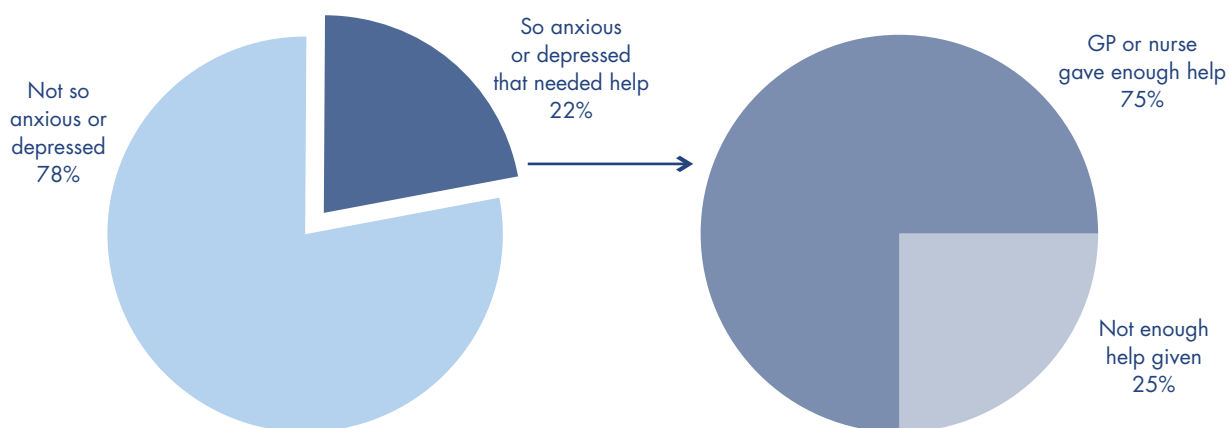
**2.27** Approximately one fifth of patients reported suffering anxiety or depression so serious that they needed help after discharge, of which one quarter stated they did not receive adequate help, **Figure 40**. This means that 5 per cent of all patients who responded on this point needed, but did not receive, enough help for their anxiety and/or depression.

**2.28** Within the overall picture London patients received less support than others (**Figure 41**).

**41** A lower proportion of anxious or depressed cancer patients in London received the support they wanted than elsewhere



**40** One in five cancer patients felt so anxious or depressed after leaving hospital that they needed help and one quarter of those did not receive enough help



**2.29** There are examples of how integrated supportive care can be offered for patients after leaving hospital, as shown in **Box 1**.

The majority of patients feel that their religious and cultural beliefs were suitably taken into account, but a minority of patients had no access to a religious counsellor

**2.30** Patients do not always have strong religious beliefs but National Institute for Clinical Excellence guidance states that, where they do, they should have access to staff who are sensitive to their spiritual needs and these staff should have access to suitable spiritual care givers. Over half of the patients in our survey reported that they had no strong religious beliefs. As few as four per cent of all cancer patients felt these had not been catered for (see **Figure 42**). In other words, over 90 per cent of those with strong religious beliefs felt that they had been taken into consideration by hospital staff. Twelve per cent had no access to a religious counsellor, but half of these did not have strong religious beliefs.

BOX 1

Providing integrated psychosocial support

The Princess Royal Hospital, Hull, has a well-established department offering psychological support embedded within its oncology service. Drawing on research which showed that, by applying basic principles of psychological management, a great deal of distress could be prevented and that the use of simple, self-help interventions could enhance quality of life, they established an Oncology Health Centre. This consists of a nurse-led "drop-in" centre that patients and their families can visit without an appointment, whether inpatients or outpatients. Trained staff are available to provide individually-tailored information, and patients and carers can meet and exchange experiences with other patients and carers. There is also a psychologist-led service, to which any local clinician can refer. A second centre has now been added at another site within the Trust.

Most patients referred by health professionals were referred in the community. Deprived patients are well represented among users.

Carers in a NAO focus group were very enthusiastic about the work of the centre, and continued to make use of it after the death of their spouse.

**2.31** The NHS should be capable of responding sensitively to the diverse nature of communities it serves.<sup>9</sup> Among our respondents, roughly 100 people from black and minority ethnic background answered the questions about religious beliefs and more than three quarters had strong religious beliefs. They were more likely to say that their religious beliefs had not been taken into account than patients as a whole, and four in ten of those (excluding "don't knows") reported that a religious counsellor had not been available. However, this remains an area where little research has been done. In our focus groups there was a general feeling among all groups that attempts were made to provide religious support, although there were difficulties for minority group members in geographical areas where there were few minorities. Afro-Caribbean women felt strongly that their existing local spiritual support network was always their first port of call.

42

The overwhelming majority of patients for whom it was important felt that their religious needs were met by hospitals

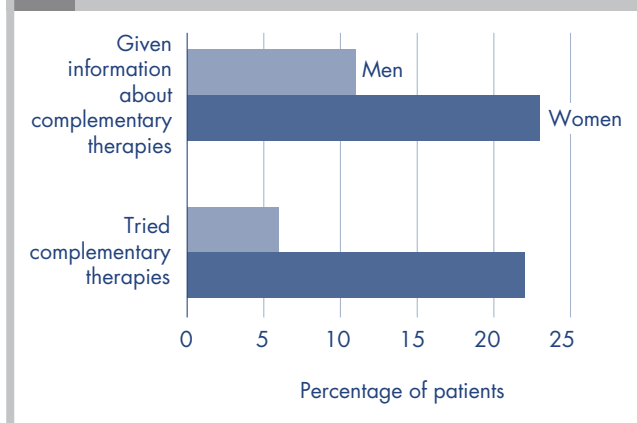
		Did you have access to a hospital chaplain or other religious counsellor if needed?			
		%			
		Yes	No	Don't know	Total
Were religious beliefs adequately taken into account by the hospital staff treating you?	Yes	31	4	8	43
	No	1	2	1	4
	No strong religious beliefs	22	6	25	53
	Total	54	12	34	100

9 Meeting the Religious and Spiritual Needs of Patients and Staff. Department of Health (2003).

Cancer patients who used complementary therapy services were enthusiastic for what they see as their benefits, but provision of information about these services was not widespread within the NHS

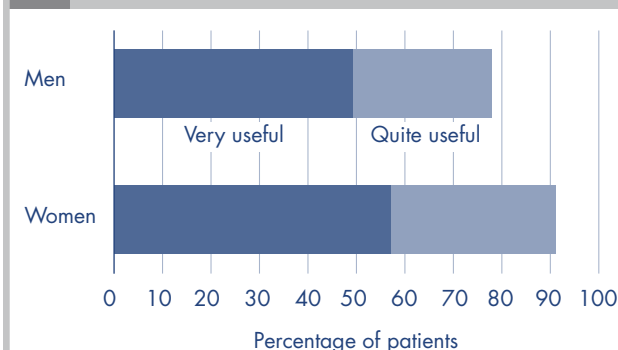
**2.32** Some complementary therapies have become increasingly popular with patients because of the positive effects that patients perceive in helping them to feel better. Their purpose is not to inhibit the advance of cancer, since there is no evidence to support their use for this purpose and doctors have been concerned that such therapies might raise false hopes or even be harmful if they lead to patients refusing effective conventional treatments. National Institute for Clinical Excellence guidance, published in March 2004, as the survey was carried out, states that, as a minimum, high quality information should be made available to patients about complementary therapies and services. Only fifty per cent of the patients in our sample who had tried complementary therapies had received information about them from their hospital.

**43** Only a small proportion of women, and even smaller proportion of men, had been informed about complementary therapies or made use of them in 2004



**2.33** Usage of complementary therapies was still the exception rather than the rule, **Figure 43**. The proportion of patients using them declined sharply with age. Among those who had tried complementary therapies, the large majority found them useful, **Figure 44**.

**44** Of some 600 women and men who had tried complementary therapies, a large majority of both found them "very" or "quite" useful



## PART THREE

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



The transition from hospital to community worked well for most cancer patients, but not all received information and home circumstances were not always taken into account in arranging discharge

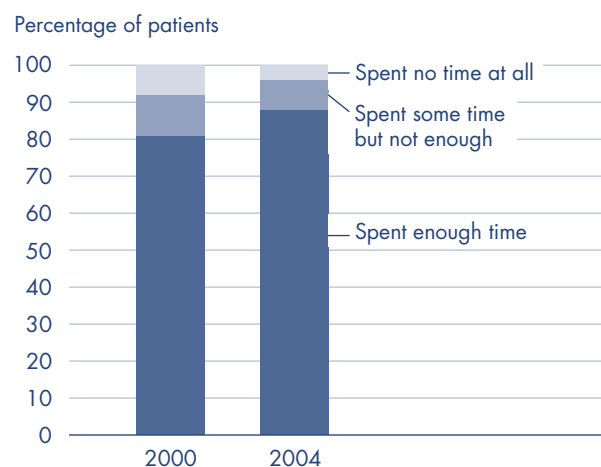
Most patients reported that they were well informed and knew what to expect when leaving hospital

**3.1** Cancer patients who require further care once they leave hospital should have a smooth transition to, and appropriate information about, the full range of NHS and voluntary sector supportive and specialist palliative care<sup>10</sup> services available, including 24 hour care.

**3.2** In 2000, the majority of patients gave positive responses to questions about the way their transfer from hospital care was organised, though some gaps were identified in respect of discussing continuing health needs and information flows about further support available in the community. By 2004, nearly 90 per cent of patients felt that about the right amount of time was taken to explain things, **Figure 45**. The proportion who had no discussion halved to 4 per cent.

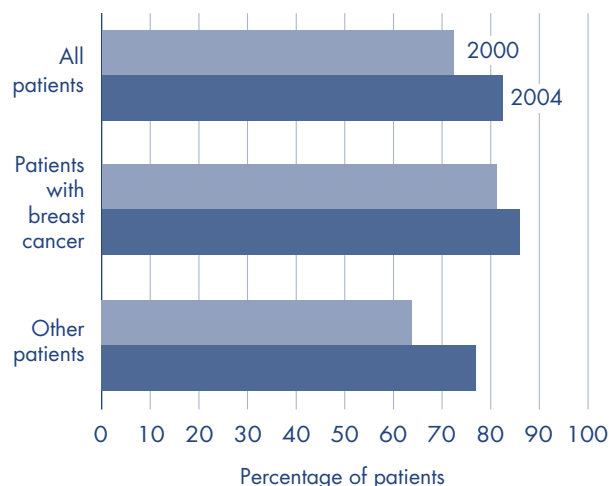
**3.3** It is helpful for patients if they have access to written information about what happens next. This provides a source which can be referred to later on as needed and avoids the risk of overburdening patients at a busy time. **Figure 46** shows that while there had been an improvement since 2000 across all cancer patients, one in five still did not receive such information. The variations between cancer types were smaller than in 2000, though breast cancer patients continued to get information more frequently. Fewer of the oldest patients were provided with information – 76 per cent of patients aged over 80 received written information about what to do after leaving hospital compared to 83 per cent of other ages. Work to improve the provision of information is illustrated at Appendix 4.

**45** By 2004, almost all patients received information about what would happen after leaving hospital



**46** More patients were given printed information on leaving hospital in 2004

Although patients with breast cancer were still more likely to receive printed information than other patients, the gap had closed from 17 to 10 per cent.



10 Palliative care gives relief from pain and other symptoms, but does not cure disease.

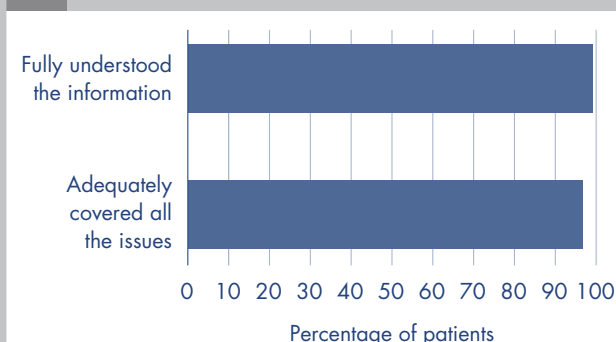
## Patients were satisfied with the information provided if they received it

**3.4** Among patients who received information, satisfaction with its content was almost universal, **Figure 47**.

**3.5** Patients should have a discussion with staff about whether they will require healthcare from the NHS or elsewhere after leaving hospital (**Figure 48**). Patients with bowel and lung cancer may be more likely to require

further care (e.g. from community nurses) after leaving hospital. It is not surprising therefore, that discussion of their further healthcare needs was commonest for these two groups. Breast cancer patients indicated most often that a discussion of these issues was lacking when it would have been helpful. In regional terms, cancer patients in London were less likely than patients elsewhere to have a discussion about these needs when it would have been helpful.

### 47 Virtually all patients were satisfied with the clarity and scope of the written information



## Home circumstances were not considered in arranging the discharge of a fifth of cancer patients

**3.6** Patients should not be discharged without knowledge of whether they can care for themselves, or be cared for, within their home environment. There had been an increase in the proportion of patients who reported that family and home situation was taken into account, from 74 per cent in 2000 to 82 per cent in 2004, **Figure 49**. The improvement was seen across all cancers, though breast and prostate cancer patients were less likely to say that their situation had been fully taken into account. Thirteen per cent of patients with prostate cancer said no account had been taken of their home situation.

### 48 16 per cent of patients either did not discuss further healthcare needs or they were discussed but not provided

	All patients %	Patients with breast cancer %	Patients with bowel cancer %	Patients with lung cancer %	Patients with prostate cancer %	London patients %	Patients from elsewhere %
Discussed and help provided	39	32	49	47	35	33	40
Discussed but help not provided	4	4	4	5	3	5	4
No discussion, but one would have been helpful	12	14	11	9	9	17	11
Not applicable	45	50	36	39	53	45	45

### 49 Just over four in five patients report that their home situation was fully taken into account when being discharged from hospital

	All patients %		Patients in 2004 with the following cancers %			
	2000	2004	Breast	Bowel	Lung	Prostate
Home situation:						
Fully taken into account	74	82	78	88	86	79
Partly taken into account	11	9	11	6	7	8
Not taken into account	15	9	11	6	7	13

Forty per cent of patients were not given information about relevant cancer support groups, though coverage of such groups varies by cancer type

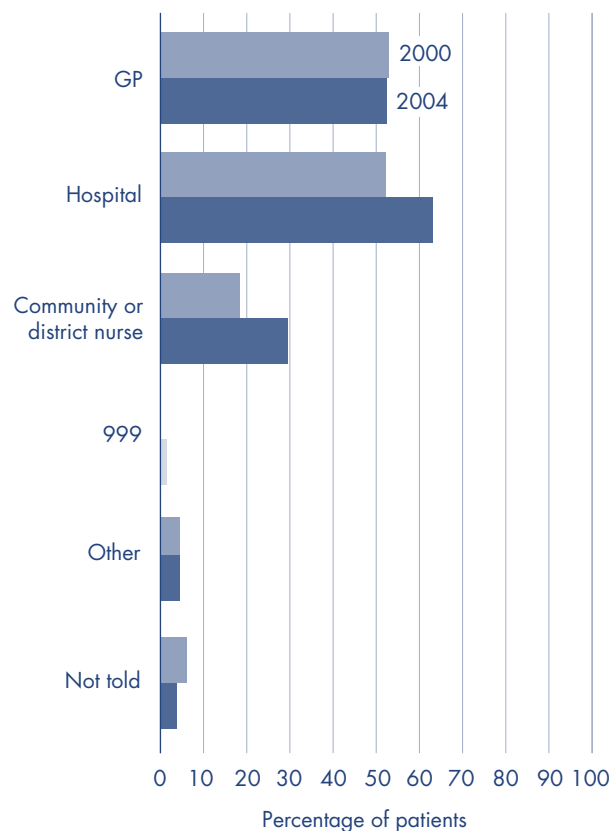
**3.7** Support groups can be an important source of information, advice and peer group support for patients following their discharge from hospital. Networks of support groups are far better developed for patients with some cancers, particularly breast cancer, than for others, so variation in the provision of information is to be expected, **Figure 50**. However, although information about support or self-help groups provided to lung cancer patients increased between 2000 and 2004, it decreased for the other three major cancer types.

After leaving hospital, most patients got the help they needed from the NHS and thought it met their needs very well

**3.8** National Institute for Clinical Excellence guidance in supportive and palliative care published in 2004 requires cancer patients to be made aware of a contact point if problems arise following discharge. Even as this guidance was being introduced, however, 96 per cent of cancer patients in our survey were already given a contact point (**Figure 51**).

## 51 Hospitals and community nurses were more likely to be given as contact points after discharge in 2004

There has been a rise in hospitals and community nursing services as contact points for patients post-discharge.



## 50 The proportion of patients reporting being given information on support or self-help groups is still around 60 per cent

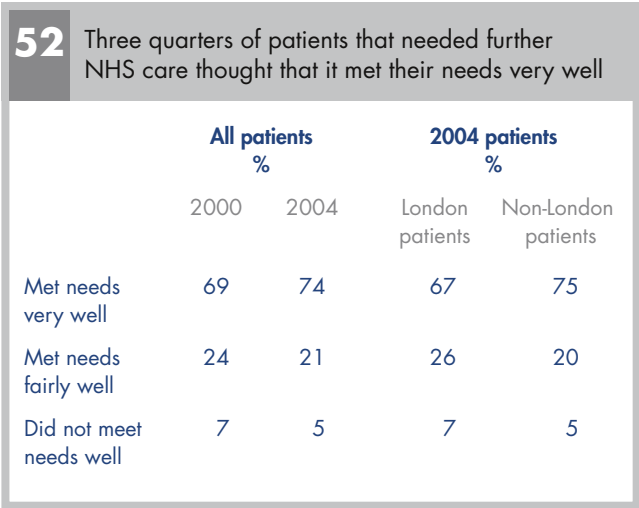
Twice the proportion of patients with breast cancer received this information as patients with prostate cancer.

	All patients %*		Patients with breast cancer %		Patients with lung cancer %		Patients with bowel cancer %		Patients with prostate cancer %*	
	2000	2004	2000	2004	2000	2004	2000	2004	2000	2004
Told about group	61	60	73	70	54	63	57	53	36	34

NOTE

\* Change over time not statistically significant

**3.9** When patients required further care specifically from the NHS, 19 patients out of 20 thought that it met their needs "very" or "fairly" well (**Figure 52**). The proportion who thought it had met their needs very well had increased by four per cent since 2000. Londoners were less likely to say that their needs had been met very well.



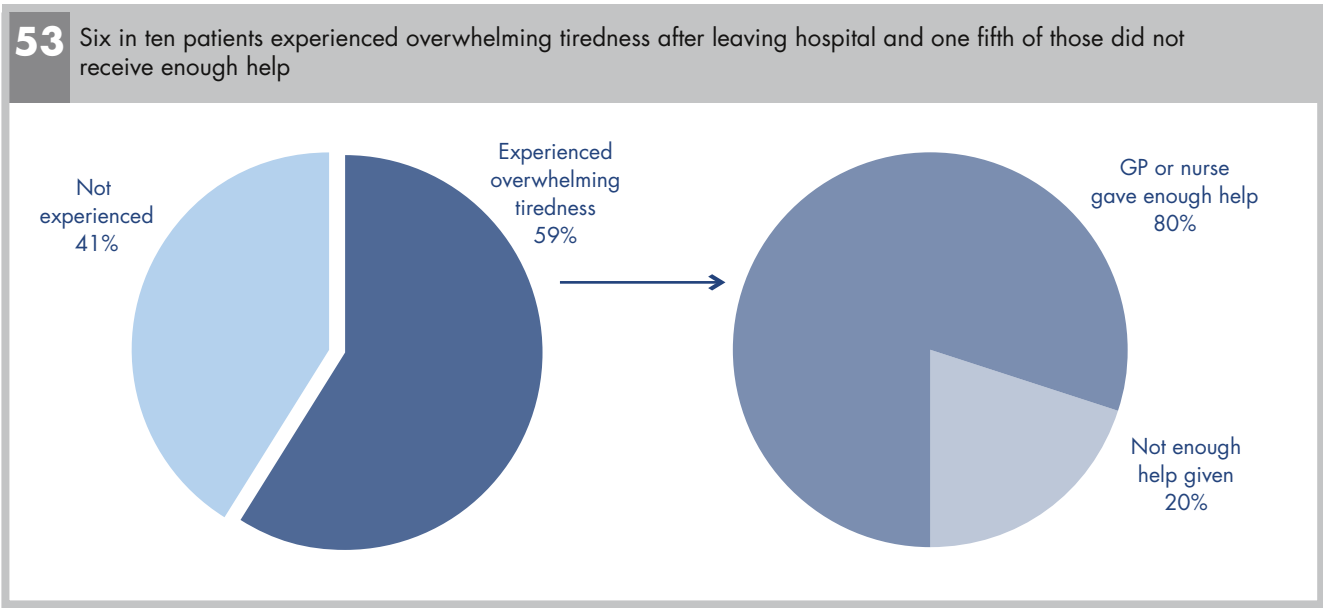
Patients frequently experienced fatigue and, in a fifth of these cases, patients thought they did not get sufficient help

**3.10** Another frequent effect of cancer and its treatment is overwhelming tiredness, which was reported by 59 per cent of cancer patients in the survey (**Figure 53**). Fatigue is, together with pain, among the most frequently

reported symptoms of cancer, but its causes and treatments are only partly understood. In total, 12 per cent of cancer patients experienced overwhelming tiredness but did not feel that they had been given enough help to cope with it.

Most patients lacked access to advice about financial benefits though many want it

**3.11** Patients with cancer often need information and help with their financial situation as well as their physical and psychological state. Cancer patients may be off work for long periods or may no longer be able to work at all. Their relatives and carers may need time off work, again with an associated loss or reduction in income. Three quarters of the patients in our survey who could remember reported that they had not been given information about benefits by anyone, but half of this group – approaching one third of all cancer patients in our sample – would have liked such advice, **Figure 54**. Within the small proportion receiving advice, women were less likely than men to receive it (19 per cent of women against 28 per cent of men received benefits advice), although they would have liked to receive it just as much. The gender imbalance is the result of differing experiences for men and women with bowel cancer (30 per cent of men given advice versus 20 per cent of women). The House of Commons Public Accounts Committee recommended in 2003<sup>11</sup> that the Department for Work and Pensions should make greater use of contacts with local health services to promote take up of disability-related benefits.



11 HC 565, 2002-03.

**3.12** Lung cancer patients in particular are likely to suffer from high levels of disability associated with their cancer and be from less advantaged backgrounds. As a result, they are likely to need advice on benefits more than other groups of cancer patients. It is encouraging therefore that patients with lung cancer were much more likely to be offered benefits advice than other cancer patients, **Figure 55**, but there was nevertheless still much unmet need for advice about benefit entitlements.

"in two months, no social support was suggested; carers' and attendance allowance were not mentioned or suggested".

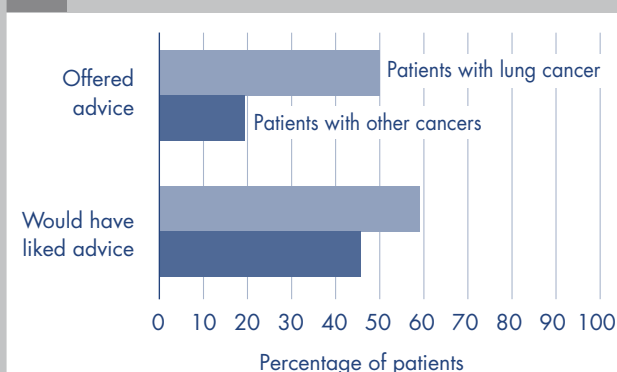
*Focus group carer*

**3.13** Disability Living Allowance (DLA) and Attendance Allowance (AA) are non-means tested benefits that can be claimed by those with severe disabilities under and over the age of 65 respectively, but under special rules are also available to the terminally ill (for these purposes terminally ill means someone who is not expected to live longer than six months). Research carried out on behalf of Macmillan Cancer Relief<sup>12</sup> in 2004 estimated that, in 2001, English terminally ill cancer patients failed to claim DLA and AA worth £106 million in six months. Since there are no reliable estimates of the level of take-up among cancer patients, the researchers assumed that those who died of cancer in the period were not expected to live longer than 6 months, thus qualifying them for benefit.<sup>13</sup> The Macmillan research estimate is, therefore, a theoretical maximum amount of DLA and AA foregone. Reasons why the real figure would be less than this are that:

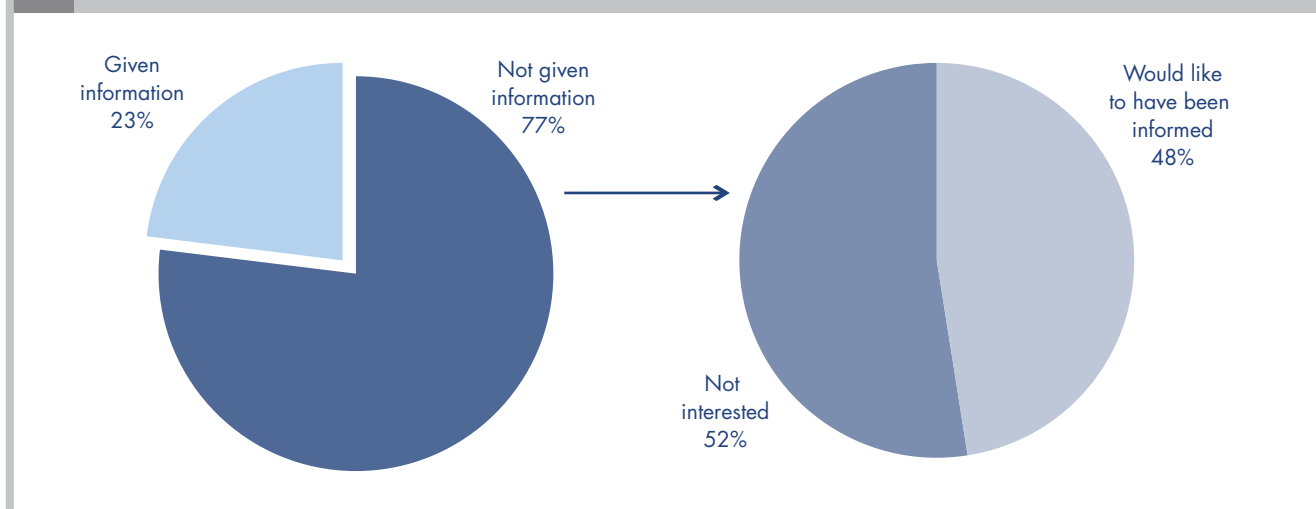
- some of those who died would have had a better prognosis but suffered an unexpectedly early death;
- people with multiple disabilities are awarded DLA and AA in respect of the combined care and mobility needs arising from the different disabilities, but only one disability will be recorded as the reason for their claim. Patients with cancer may receive the allowances under a different heading; and
- people who have a limited time available to them may have other priorities, finances permitting.

In overall terms, claims and payments for DLA and AA have increased 29 per cent and 12 per cent between the introduction of the benefits in their current form in 1992 and May 2004 (5 and 6 per cent respectively in the most recent 12 month period).

**55** Patients with lung cancer were much more likely to be offered advice on benefits but were also more likely to have an unmet need for advice



**54** Over three quarters of patients were not given advice on financial or other benefits by the NHS or others, but nearly half of those would have liked such information



<sup>12</sup> Lee and Allirajah. The unclaimed millions: DLA and cancer patients. Welfare Rights Bulletin 181, 2004.

<sup>13</sup> There were 57,701 cancer-related DLA and AA claims (reported by the Department for Work and Pensions) and 127,076 cancer deaths (reported by the Office for National Statistics).

**3.14** Macmillan researchers were not able to estimate what additional means-tested benefits patients may have foregone. The care or mobility needs of these patients may or may not be sufficient to meet the usual entitlement conditions for other benefits apart from DLA and AA.

**3.15** Macmillan also researched barriers to benefit take-up among cancer patients.<sup>14</sup> Among the reasons given by the research for failing to claim benefit were: health professionals' lack of knowledge of the benefit system; a reluctance to confirm that the patient has less than six months to live (required for these benefits to be payable); patients' lack of awareness about benefits to which they may be entitled and how to claim them; and reluctance by patients to claim because of a stigma about claiming benefits. Take up also appeared to be higher in areas with higher levels of existing benefit claims.

Patients were generally more positive about their most recent outpatient visit than about care at the time of first treatment, but appointments were becoming more delayed on the day

Patients spent more time with doctors and nurses at their most recent outpatient visit than in 2000, but appointments still rarely ran to time and could be cancelled

**3.16** More than 90 per cent of patients had attended an outpatient appointment in the two years before our 2004 survey. Only just over one in ten had experienced a cancelled appointment, an improvement over 2000, **Figure 56**. Prostate cancer patients experienced significantly more cancellations than other patients. A similar pattern was seen in 2000.

**3.17** There was an increase in the proportion of outpatient appointments lasting longer than 20 minutes, **Figure 57**. Despite this, the proportion of patients who said that appointments were too short remained virtually unchanged at 8 per cent – slightly more for patients with breast cancer. Seventy per cent of patients who said their appointment was too short spent less than ten minutes with the doctor.

## 56 In 2004, slightly fewer patients had had their most recent outpatient appointment cancelled

	All patients %		2004 patients %	
	2000	2004	Patients with prostate cancer	Patients with other cancers
Not cancelled	87	88	81	89
Cancelled once	11	10	15	9
Cancelled more than once	2	2	4	2

## 57 Patients spent longer with clinicians at their last outpatient appointment in 2004 than 2000

Patients with breast cancer had noticeably shorter consultations than other patients.

Length of consultation	All patients %		2004 patients %	
	2000	2004	Patients with breast cancer	Patients with other cancers
Less than 10 minutes	31	23	30	16
10 to 19 minutes	52	52	50	52
20 to 29 minutes	13	20	16	25
30 minutes or more	4	5	4	7

**3.18** People rarely saw their doctor at the appointed time, **Figure 58**. The proportion of patients waiting more than 30 minutes past the due time has increased from 36 per cent in 2000 to 42 per cent now. Almost one in five waited more than one hour. Patients were most likely to wait longest in clinics run by teaching hospitals, followed by specialist hospitals, **Figure 59**.

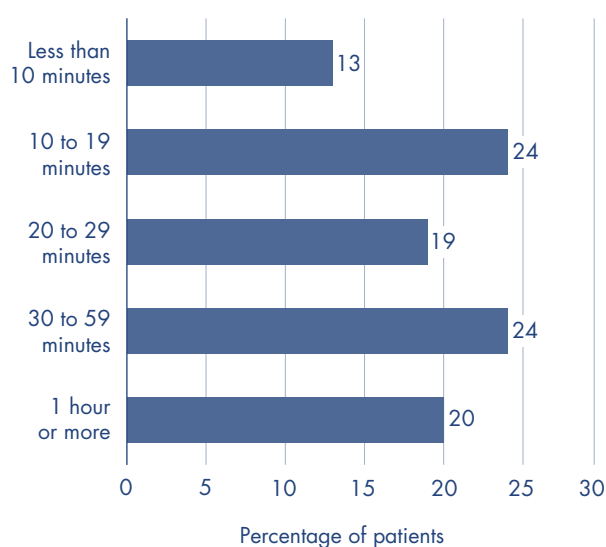
14 Lee and Allirajah. The unclaimed millions: DLA and cancer patients. Welfare Rights Bulletin 181, 2004.

## Outpatients had very high levels of privacy during examinations

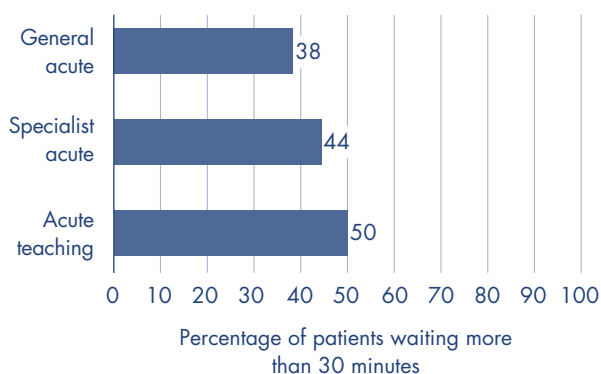
**3.19** Outpatients reported the same degree of privacy as inpatients during their examination, but more also had enough privacy during discussions, **Figure 60**. In 2000, 99 and 100 per cent of patients said they had enough privacy during examinations and discussions respectively.

### 58 Almost one in five outpatients wait more than one hour after the appointed time to see a doctor

Wait after time of appointment



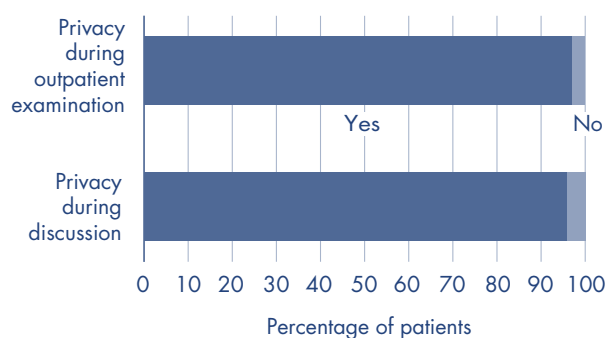
### 59 Doctors are more likely to see patients 30 minutes later than their appointment time in some types of hospital than in others



## There has been a sharp increase in the proportion of outpatients expressing a lot of confidence and trust in their doctor

**3.20** There has been a marked increase over the past 4 years in the proportion of cancer patients expressing 'a lot' of confidence and trust in the doctor who saw them at their most recent outpatient visit (**Figure 61**). This was particularly the case for patients with breast and prostate cancer. Patients in London are less likely to have a lot of confidence and trust in the doctor seen at the most recent outpatient visit (78 per cent versus 85 per cent elsewhere). Confidence and trust in doctors seen in the outpatient clinic increased with age of patient in our survey (**Figure 62 overleaf**). We are not able to say whether this reflects a better service or a more accepting attitude on the part of older cancer patients.

### 60 Outpatients experienced very high levels of privacy



### 61 The proportion of patients expressing a lot of confidence in the doctor seen at their most recent outpatient visit has increased sharply since 2000

	Confidence and trust in doctor at last outpatient visit %	
	2000	2004
A lot	68	84
A fair amount	27	13
Not much/none	5	3

## Despite recent initiatives, the availability of specialist palliative care services in the community varies

Additional budgetary resources have developed specialist palliative care services, but coverage is not even across England

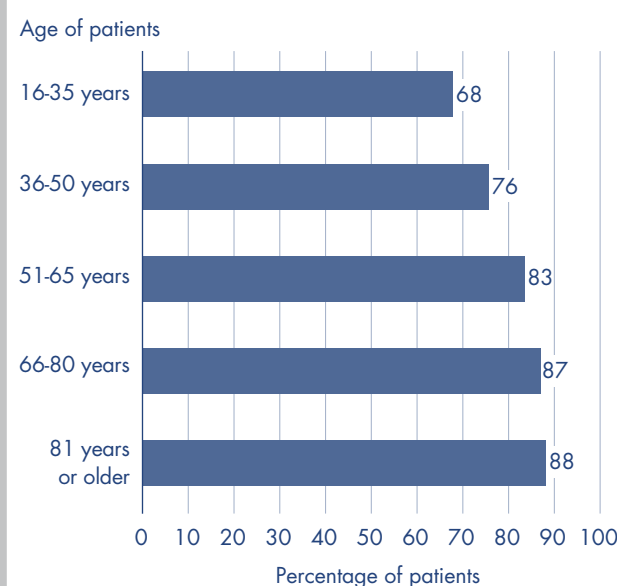
**3.21** Much of the care for patients with advanced incurable illnesses is provided by 'generalists', such as GPs, district nurses and hospital doctors. Many patients, however, need assistance from professionals who specialise in palliative care. Specialist palliative care services are most effectively delivered by multi-professional teams, whose staff are specially trained to advise on symptom control and pain relief and to give emotional, psychological and spiritual support to patients, their families, friends and carers, both during the patient's illness and into bereavement. Absence of such care could lead to unnecessary emergency admissions to hospitals. National Institute for Clinical Excellence guidance on supportive and palliative care notes that:

"Many hospitals do not have full multidisciplinary teams who can provide advice on a 24-hour, seven days a week basis. Community specialist palliative care services vary considerably in their ability to provide services at weekends and outside normal working hours. The number of specialist palliative care beds per million population varies widely between Cancer Networks".

**3.22** The Department has established an annual £50 million central budget to develop specialist palliative care services for three years from 2003-04. The extra £50 million is specifically to meet the commitments in the NHS Cancer Plan. It is to help tackle inequalities in access to specialist palliative care, and to enable the NHS to make a realistic contribution to the costs hospices incur in providing agreed levels of service. The Big Lottery Fund (formerly the New Opportunities Fund) is also making grants of £45 million to the development of adult palliative care services, concentrating on rural and inner city areas.

**3.23** Current levels of specialist palliative care provision vary greatly around the country and do not necessarily reflect the areas of greatest need (**Figure 63**). The resource need for home care, day care and hospital support services is not directly linked to population levels. In order to help commissioners direct the money to where it is most needed, the Department of Health commissioned the National Council for Hospice and Specialist Palliative Care Services (now the National Council for Palliative Care) to produce a population based needs assessment for palliative care.

**62** The proportion of patients who, at their last outpatient appointment, had a lot of confidence and trust in the doctor increases with age



**63** Existing specialist palliative care services in England are distributed unevenly

Hospice and specialist palliative care services: NHS and voluntary sector inpatient beds (per thousand cancer deaths)	
London	51
Midlands and East	32
North	34
South	44
England	38

Source: Inpatient beds – Hospice Directory, position as at January 2003  
Cancer deaths – National Centre for Health Outcomes Development, Compendium of Clinical and Health Indicators 2003 (provisional release) based on ONS data

#### NOTE

For cancer mortality, figures for the four Directorates of Health and Social Care have been compiled from data for the Government Offices for the Regions.

This was published in May 2004 and is designed to be used by Cancer Networks to establish service gaps in their areas and devise plans to address them. As an example, the level of need was found to vary by as much as 100 per cent between PCTs within the Greater Manchester and Cheshire Cancer Network.

## Hospices told us that staff and other resources remain constraints and a wider range of services should be provided

**3.24** There are 130 voluntary hospices, with over 2,000 inpatient beds (NHS palliative care units provide fewer than 500 beds). They also offer a range of day and home care services, sometimes including hospice-at-home services<sup>15</sup> and support therapies. Local specialist palliative care consultants and nurses may be wholly or partly employed by the hospice in some areas. Seventeen per cent of terminally ill cancer patients die in a hospice.

**3.25** During our visits to hospitals and hospices we were told by staff involved in palliative care that the new Departmental funding and the National Institute for Clinical Excellence guidance were welcomed as they indicated that palliative care was now a priority for the NHS, but that challenges remained – some arising from the sector's success. Hospice staff reported:

- continued shortages of specialist staff. There was a general shortage of specialist palliative care nurses and many unfilled consultant posts, some unfilled for many years. Shortages of such posts are not universal – there are considerable inequalities between geographical areas. The additional funding for specialist palliative care provided by the Department is helping to recruit 63 additional palliative care consultants and 168 cancer nurse specialists;
- pressure to widen the range of services offered to outpatients with chronic illness attending for treatment or support, and extension of services to non-cancer patients (over 90 per cent of palliative care is currently delivered to cancer patients);
- increased demand for core services, with the referral of increasingly dependent patients;

- pressure on staffing pay and terms and conditions of employment. The adoption of the Agenda for Change programme in the NHS means that hospices feel under pressure to review their terms and conditions of employment in order to remain competitive with other alternatives when recruiting specialist staff;
- limits on funding. Estimates vary, but hospices receive on average approximately one third of their funding from the NHS. Hospices expressed concerns to us that income from voluntary contributions from sources such as legacies will decline in the future due to competition from other good causes and the consumption of funds during people's lifetimes; and
- challenges in achieving referrals to hospices from a less "middle class" base. In particular black and minority ethnic patients are under-represented among patients in hospices. One of the hospices we visited had commissioned their own research to find out why (see Box 2).

## BOX 2

### Improving access to palliative care for ethnic minority groups

St.Catherine's Specialist Palliative Care Centre in Crawley commissioned research to find out why their services were rarely used by the 8 per cent minority population of Crawley, mainly of South Asian origin.

The research established that there were two main reasons:

- Minority patients were three times less likely to be aware of the Centre's services. Knowledge of its services was often passed on among the general population through informal social interaction and information networks. Minority groups were often excluded from these networks, especially women; and
- These groups often felt a strong sense of moral and religious duty to restrict the care of sick or dying relatives within the extended family unit. However, it was recognised within these groups that succeeding generations were moving away from these practices.

In response to the report the Centre has employed a Cultural Liaison Officer and a senior member of a local minority group has joined the Board of Trustees.

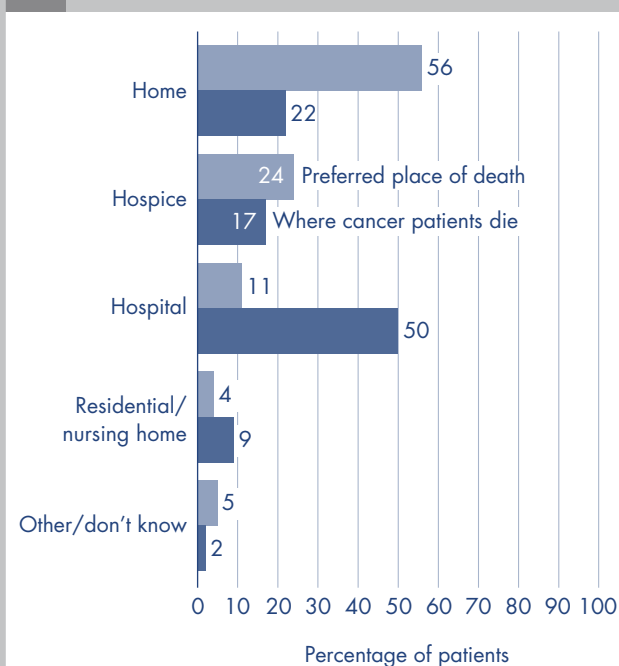
<sup>15</sup> Hospice-at-home is a service that provides care for both patients and their families that allows patients to spend the last days of their life at home.

## Cancer patients often do not die in their place of choice

**3.26** Terminally ill cancer patients generally have views about where they would like to spend their final days and die, supported by a community specialist palliative care team. A recent telephone survey of the end of life preferences of members of the public, **Figure 64**, shows that there is a major disparity between the preferences expressed by the public and the experience of those dying from cancer. The biggest divergence between wishes and outcomes is that more patients die in hospital but wish to be at home. Recent Department of Health-funded research in the North West, based on interviews with about 40 cancer patients in the last months of their life, showed that home, hospice or "still not decided" were equally favoured, but none wished to die in hospital.<sup>16</sup>

**3.27** In order to improve support for patients at the end of their life, the Department of Health is making available £12 million over three years from 2004-05 to fund an End of Life Care initiative. This is intended to promote the wider adoption of several best practice models: the Gold Standards Framework (**Box 3**), the Liverpool Care Pathway (**Box 4**) and the Preferred Place of Care initiative, which the Lancashire and South Cumbria Cancer Network developed as a tool to encourage patients and professionals to discuss their preferences for end of life care.

### 64 Research indicates that cancer patients often do not die in their location of choice



Sources: Department of Health place of death figures (2001 and 2002); Higginson. *Priorities and preferences for end of life care in England, Wales and Scotland*. National Council for Hospice and Specialist Palliative Care (2003)

16 Place of Death in the Morecambe Bay Area. Lancaster University Institute for Health Research (2003).

## BOX 3

### The Gold Standards Framework

The Gold Standards Framework (GSF), is a programme to encourage best practice in community palliative care. It was developed by a multidisciplinary reference group backed by Macmillan Cancer Care. The aim is to develop a locally based system to optimise the quality of care for patients in their last year of life. The GSF is a 3-step process to identify, assess and plan care for patients around their needs. The framework suggests small but key changes that can be tested out, modified, adapted then extended as appropriate within the areas of the seven 'gold' standards to encourage and enable practices to improve care for patients. The seven standards cover:

- Communication (including patient preference for place of care);
- Co-ordination;
- Control of symptoms;
- Continuity out-of-hours;
- Continued learning;
- Carer support; and
- Care in the dying phase (linked to the Liverpool Care Pathway).

It is currently used by about one fifth of GP practices across the UK.

From January 2005 the NHS End of Life Care programme continued funding of the GSF support programme.

## BOX 4

### The Liverpool Care Pathway for the Dying Patient

The Royal Liverpool University Hospital Specialist Palliative Care Team carried out a review of deaths in the hospital that established that they had only had contact with about 15 per cent of the patients who died in the hospital. The Hospital set up a multidisciplinary steering group with Liverpool Marie Curie Centre. They developed an integrated care pathway for dying patients (the LCP) consisting of 3 stages:

- Initial assessment and care. Dying is diagnosed, based on patient weakness, confinement to bed and inability to take food, drink and medication;
- Ongoing care. Symptom control is reviewed every few hours and psychological and spiritual support provided for patient and family; and
- Care of family and carers after the patient's death. This includes information needs and special requests for care of the body.

National Institute for Clinical Excellence supportive and palliative care guidance cites the LCP as a model of care for dying cancer patients, and it can be applied in hospital, hospice, community or nursing home settings. In our visits to hospitals and hospices, we found widespread enthusiasm for the LCP as a means of integrating care for the dying by bringing together different professional groups and providing a framework to help busy staff ensure the completeness of care procedures. It is now being applied in over 100 centres.

# APPENDIX 1

## Methodology

### Survey of cancer patients

**1** In conjunction with Picker Institute Europe, who played a central role in the original NHS Cancer Patient Survey, we developed a questionnaire with just over 100 questions covering diagnosis, first hospital treatment, leaving hospital and most recent outpatient appointment. The 2000 survey was a very extensive investigation of the performance of the NHS as seen from the cancer patient's perspective and covered 65,337 respondents from 172 hospital Trusts.

**2** The main aim of our work was to track changes since 2000. Accordingly, most of these questions followed the wording of questions in the NHS National Cancer Patient Survey of 2000, in order to provide comparison with the results from the earlier survey. Thirteen additional questions were asked on some topics, for example the provision of supportive and palliative care after leaving hospital. A leaflet was enclosed with each questionnaire which explained in the most commonly spoken non-English languages how to access interpreter assistance in completing the questionnaire.

**3** Through consultation with the Commission for Health Improvement, we were aware that they and the Stroke Audit Group also planned to carry out two surveys of Acute Trusts in a similar timeframe to our own, in connection with their work on coronary heart disease and stroke. We worked with the Picker Institute to ensure that sampling of Trusts was done in such a way that selection remained random without any Trust being selected for more than one survey.

**4** For each survey, Trusts were stratified into two groups: specialist Trusts (which had patients eligible only for that survey, specialist oncology centres in the case of cancer) and overlapping Trusts (which had patients eligible for all three surveys). For each survey, the number of Trusts drawn from each stratum was proportional to the distribution of specialist and overlapping Trusts for that survey. The first step was to sample the appropriate number of specialist Trusts for each survey in turn. Then, for the sampling of overlapping Trusts, the combined sampling process was to sample one Trust for each survey in turn.

**5** A minimum required sample size of 7,800 was estimated by the Picker Institute. Sampling carried on until the number of Trusts reached 54 for the NAO Cancer Survey. In the event, one Trust was excused because it had carried out similar work in the recent past, and four others did not supply data within the required timescale. The remaining 49 Trusts provided a sample of respondents (7,800) large enough to allow statistically significant differences to be identified at the national level and across cancer types, if they existed, between the results of the 2000 NHS National Cancer Patient Survey and our own carried out in early 2004. The sample of Trusts used was also sufficient to provide a representative mix of respondents by type of cancer. This methodological approach was discussed with, and approved by, statisticians from the survey section of the Department of Health, the Commission for Health Improvement and their contracted advisors on patient surveys in advance of the survey being run.

**6** Because of the sensitivities involved in undertaking this work, before doing so we confirmed the NAO's legal position with our lawyers. In summary, this legal advice said that Section 8 of the National Audit Act (1983) provided us with the right of access to patient records. Although we had the right of access to these documents, we could not compel the Trust to compile and send a list of patients to us. We were open about this to Trusts and, subject to assurances of confidentiality, they were happy to send us the information. We discussed our methodology, including data protection issues, with the Patient Information Advisory Group.

**7** Having contacted both the Central Office for Research Ethics Committees (COREC) and the Metropolitan Multi-Centre Research Ethics Committee (MREC) we received a letter from the Chair of the Metropolitan MREC, stating that she was satisfied that, as our work was an audit rather than research, we did not need ethical approval. COREC's view was that the Chair was of sufficient standing and experience to take a formal view on this matter.

**8** Questionnaires were sent out to all patients from 49 acute Trusts across England who had been diagnosed with the four major cancers – breast, lung, bowel and prostate – and had been discharged from the Trust in the previous three months. The four cancers covered are those we examined in detail in our first report on cancer, *Tackling Cancer: Saving More Lives*. The particular advantages of this were that:

- It provided consistency with our earlier work;
- The size of the Trust was represented accurately by the number of patients; and
- It was simple for Trusts to understand which patients are eligible to be included in the study, rather than having to ask them to draw a random sample.

**9** In addition to the four main cancers our survey covered, the 2000 NHS National Cancer Patient Survey also covered ovarian cancer and lymphomas. We do not comment on developments with respect to these two cancers, and the results for these two cancers were excluded for the purposes of analysis of changes over time.

**10** A copy of the questionnaire is available on our web site at [www.nao.org.uk](http://www.nao.org.uk). Questionnaires were despatched in February 2004. Prior to mailing, checks were carried out to ensure that the patient's death had not been registered since the original selection. No reference was made to the patient's diagnosis, as some patients are not aware of their condition. The term "condition" was used as relevant. A reminder letter was sent where necessary; in March 2004. 4,323 completed responses were received from an original sample of some 7,800 patients – a response rate of 55 per cent.

**11** The distribution of responses from our survey and the 2000 NHS National Cancer Patient Survey are shown in **Figures 65-68**. Regional boundaries changed after 2000 so a direct comparison by area is not possible. The London area remained unchanged, however, and was represented in the responses to almost exactly the same extent as in 2000. This is important because of the less positive responses from London patients. Distribution by gender is the same. Distribution by deprivation quartile cannot be done for both surveys, but we have established that deprivation did not impact on patient experiences in any statistically significant way in 2004.

## 65 Regional distribution

Former NHS Directorate of Health and Social Care	2004 %
London	14
Midlands and East	29
North	41
South	16

## 66 Distribution by cancer type

	2000 %*	2004 %
Breast	45	47
Bowel	28	28
Lung	7	11
Prostate	20	14

NOTE

\* Excluding other cancers sampled in 2000

## 67 Distribution by deprivation quartile\*

	2004 %
Quartile 1 (most deprived)	29
Quartile 2	23
Quartile 3	22
Quartile 4 (most affluent)	26

NOTE

\* Based on patient postcode

## 68 Distribution by gender

	2000 %*	2004 %
Male	39	39
Female	61	61

NOTE

\*Excluding other cancers sampled in 2000

**12** Figure 69 compares the distribution of responses by cancer type with the proportion of cases expected according to the distribution of new cases each year of the four cancers we covered (data on prevalence rather than incidence might provide a better comparison but data for recent years are not available).

**13** The table again illustrates a marked over sampling of breast cancer patients, as well as under sampling of lung and, to a lesser extent, prostate cancer patients. These differences in response rate by cancer type will lead to bias in the results to the extent that patient experiences differ as a result merely of having one form of cancer rather than another. This effect cannot be quantified. Some elements of the patient experience should not be affected by type of cancer (other than as a result of the quality of care provided). For example, the extent to which information is provided to patients about their illness should not vary by cancer type – though it may vary if some clinical staff undertake these duties better than others. Other issues, such as the extent of pain and effectiveness of pain relief, may vary by cancer type, for instance according to whether surgery is a commonly used method of treatment. Given these issues, we were therefore careful to carry out our analyses disaggregating by cancer type.

**14** Response rates for segments of the sampled population are shown in Figure 70. As in the case of the 2000 survey, the highest response rates were from breast cancer patients and the lowest from patients with lung cancer. For the individual cancers, response rates for patients with lung cancer are always lowered in surveys of this sort because of higher levels of infirmity due to the presence of a number of co-existing conditions and significantly higher proportions of patient deaths after selection of the sample.

## 70 Patient Response rates:

### By cancer type

	Breast	Bowel	Lung	Prostate
Percentage	62	56	41	62
Numbers of patients responding	2,028	1,203	483	609

### By gender<sup>1</sup>

	Male	Female
Percentage	53	58
Numbers of patients responding	1,592	2,492

### By region

	London	Midlands & East	North	South
Percentage responding	51	56	55	60
Numbers responding	608	1,265	1,770	680

### By age group<sup>2</sup>

	16-50	51-65	66-80	Over 80
Numbers responding	628	1,455	1,711	298

#### NOTE

1 239 respondents did not specify

2 231 respondents did not specify

**15** We carried out multivariate analyses to take account of the range of possible different influences on the patient experience and to separate them out as far as possible (see Appendices 2 and 3). Given the number of respondents for some cancer types, it was not always possible to distinguish whether effects are due to random variation or would be statistically significant in a larger sample.

## 69 Distribution of survey responses by cancer type and distribution of new cases of cancer each year

	Breast	Bowel	Lung	Prostate
NAO 2004 survey response rate	47	28	11	14
NHS 2000 survey response rate	45	28	7	20
Proportion of new cancer cases each year	29	27	24	20

Source: NAO and NHS survey data and Office for National Statistics

## Supporting work

**16** In order to put the findings of the survey into context, we visited 16 hospitals and hospices across England. Hospitals were selected to be representative by type, location and star rating. Hospices were selected in consultation with the National Council for Palliative Care. We carried out structured interviews with staff involved in the treatment and provision of supportive and palliative care to patients with cancer. The subject areas covered included: patient information and communication; palliative and supportive care; availability of resources; identification of good practice; and progress in delivering service improvements.

**17** We also commissioned consultants OPM to hold focus groups and one-to-one interviews with GPs, nurses, patients and carers in three locations across England. People who took part in the study were involved through in-depth interviews (face-to-face and telephone), "mini"-group discussions and larger group sessions (see [Figure 71](#)). A topic framework for the research was designed in conjunction with the NAO and Department of Health, and individual topic guides for each of the four audiences were developed.

**18** We surveyed the 34 cancer networks in late 2003 and early 2004 on behalf of all three cancer studies to establish their views on progress in improving the patient experience in such areas as information provision. We received responses from all 34 networks. The questionnaire for this survey will be published on our web site on publication of our forthcoming study on the NHS Cancer Plan.

**71** OPM contacts with GPs, nurses, patients and carers

	GPs	Nurses	Patients/Carers
Telephone interview	2	7	5
Face-to-face interview	6	-	16
Group discussion	13	17	6

## Reference Panel

**19** We formed a joint reference panel for all three cancer studies to provide feedback on our proposed approach and initial findings. The members were

- Mary Barnes, Avon, Somerset and Wiltshire Cancer Services;
- Mitzi Blennerhassett, former cancer patient and participant in a number of patient advocacy and support groups;
- Derryn Borley, CancerBACUP;
- Dr Peter Clark, Clatterbridge Centre for Oncology and Association of Medical Oncologists;
- Stephen Dunmore, the Big Lottery Fund;
- Dr John Ellershaw, Marie Curie, Hospice Liverpool and Royal Liverpool University Hospital;
- Professor David Forman, Northern & Yorkshire Cancer registry and Information Service;
- Dr Fergus Macbeth, Velindre NHS Trust Cardiff and the National Collaborating Centre for Cancer;
- Dame Gill Oliver, Macmillan Cancer Relief;
- Professor Mike Richards, National Cancer Director;
- Professor Alison Richardson, Florence Nightingale School of Nursing and Midwifery;
- Mr Zen Rayter, Association of Breast Surgery at BASO;
- Peter Tebbit, National Council for Palliative Care;
- Jill Turner, Cancer Services Collaborative 'Improvement Partnership';
- Dr John Wiles, Harris HospisCare; and
- Julie Wood, South Leicestershire PCT.

## APPENDIX 2

### Further analysis of the patient survey: themes within the patient experience

**1** We used factor analysis to explore our data set and derive themes underlying the patient experience. Factor analysis is used to reduce a larger number of variables to a smaller number of factors based on the correlations between the original variables. Perfectly correlated variables would, for example, provide essentially the same information about a research question and can usefully be combined together as one factor to reduce complexity. The nature of the factors which emerge must however be inferred on the basis of which of the original variables load most highly on to the derived factors. The method is therefore a judgemental one, but it is potentially useful as a way of identifying summary measures, in this case, of the patient experience.

**2** The Department of Health carried out a factor analysis on the data from its 2000 National Cancer Patient Survey<sup>17</sup> and we carried out a similar analysis using our 2004 data. An exploratory factor analysis was used to group the questions in the survey into the factors comprising the 'statistical' dimensions. In order to do this, the responses to each question were first grouped to create binary outcomes. Any responses that indicate a problem were coded as "1" and all other responses were coded as "0" (representing 'no problem'). It was assumed that patients in the category 'can't say' did not have a problem and were therefore coded as "0" while those in categories 'not answered' or 'not applicable' were coded as missing cases. The Department of Health used this approach in its analysis. Our results are therefore comparable to its, though a different approach to missing data might produce different results.

**3** The questions were then fitted in a factor model restricted to produce ten dimensions. The newly created dimensions are linear combinations of the original variables and each one therefore represents a combined measure of a set of variables. Hence it does appear reasonable to measure satisfaction of cancer patients across England on these factors rather than relying on individual questions. Each factor dimension was interpreted in line with which survey questions were grouped within it, following the nomenclature adopted by the Department of Health which continued to be appropriate.

**4** The results are shown in **Figure 72** below, which lists which original variables (the questions we put to patients in our questionnaire) group into the various dimensions. The final column of the table gives the factor loadings for each original variable. Each number represents the partial correlation between the item and the factor. A higher score indicates that the original variable is more closely associated with the underlying dimension than a variable with a lower score.

**5** The ten factors collectively account for 36 per cent of the total variation in our sample. This clearly means that the factors identified sum up the patient experience in an imperfect way, but one which the Department has found useful, for example, in developing guidance for local healthcare providers to carry out simplified patient surveys that can nevertheless provide insight into the nature of the patient experience being provided. Our results confirm that this approach retains validity.

**6** The themes given to the ten dimensions are listed below in descending order of variability in the data accounted for (greatest first):

- First treatment: Respect, Trust, Hospital Management
- Understanding of Diagnosis and Treatment
- First visit: Time spent and sensitivity
- Communication and Coordination
- First treatment: Understanding and Involvement
- Information provided and Aftercare
- Recent Outpatient Visit: Care and Involvement
- Recent Outpatient Visit: Privacy
- Consideration of religious beliefs
- Access to care – waiting times

17 National Survey of NHS Patients, Cancer: Analysis of Themes, Department of Health April 2004, <http://www.dh.gov.uk/assetRoot/04/08/05/21/04080521.pdf>

## 72 The ten dimensions for measuring patient satisfaction

### Dimension 1: First Treatment: Respect, Trust, Hospital Management

No confidence and trust in hospital nurses	0.683
Not treated with respect and dignity by doctor/nurses	0.648
Insufficient nurses on duty	0.593
No confidence and trust in hospital doctors	0.588
Insufficient doctors on duty	0.544
No privacy when discussing condition with doctors/nurses	0.511
Nurses' response not easily understood	0.494
Hospital staff didn't help to ease pain	0.484
Doctors/nurses not giving consistent information	0.480
Staff involved in treatment did not provide adequate emotional support	0.465
Not enough privacy when examined by doctors	0.410
Doctors/nurses talk about patient as if patient was not around	0.396

### Dimension 2: Understanding of Diagnosis & Treatment

Doctors/nurses didn't discuss purpose of treatment with patient	0.673
Patient didn't understand his/her condition	0.645
Doctor didn't explain purpose of tests	0.621
No explanation was given on treatments available for condition	0.566
Patient not aware of treatment outcome	0.557
Patient not told of possible side effects of treatment	0.550
Written/printed information not easily understandable	0.440
Doctors' response not easily understood	0.393

### Dimension 3: First visit: Time spent and sensitivity

Patient not told of condition with sufficient sensitivity/care	0.802
Person who told patient about condition not easy to talk to	0.801
Not enough time spent on first visit	0.695
Questions answered not easily understood	0.524
Time spent on explaining condition on first visit too short	0.501

### Dimension 4: Communication and Coordination

Patient not told of support group for condition	0.623
Patient not given printed information on care after discharge	0.585
Staff didn't discuss post-discharge health services available	0.532
Patient not given printed information about treatment/condition on first visit	0.468
Patient not informed of complaint procedure	0.435
Patient not given name of nurse-in-charge	0.429
Patient not given name of doctor-in-charge	0.367

### Dimension 5: First treatment: Understanding and Involvement

Not easy to understand doctor's explanation	0.525
Patient not involved in decisions about treatment	0.440
Quality of information provided about condition/treatment	0.436
Doctors withholding information	0.394
Patient's view not taken into account	0.394

### Dimension 6: Information provided and Aftercare

Printed information given at discharge didn't cover all issues	0.611
Printed information at discharge not easily understandable	0.530
Printed information given on first visit didn't cover all areas	0.385
Inadequate care provided by the NHS	0.381
Medical advice/support/treatment not available 24 hours a day after discharge	0.381
People treating patient were not working closely together	0.376
Quantity of information provided about condition/treatment	0.363
GP not given enough information on treatment/condition	0.361

### Dimension 7: Recent Outpatient Visit: Care and Involvement

No confidence and trust in outpatient doctor	0.704
Not enough time spent by doctor with patient	0.680
Not treated with respect and dignity as an outpatient	0.501
Family not involved in patient's aftercare/treatment	0.417

### Dimension 8: Recent Outpatient Visit: Privacy

Lack of privacy during examination	0.789
Lack of privacy when discussing condition/ treatment	0.762
Not treated with respect and dignity as an outpatient	0.421

### Dimension 9: Consideration of religious beliefs

Religious beliefs not taken into consideration by hospital staff	0.752
Not enough support for religious beliefs during treatment	0.749

### Dimension 10: Access to Care - Waiting times

Condition deteriorated during waiting time	0.686
Waited too long for first appointment with hospital doctor	0.628

## APPENDIX 3

### Further analysis of differences across regions, type of cancer, and gender, and of adverse patient experiences

#### Analysis of differences by region, cancer type and gender

##### Background and approach

**1** Our analysis in the main report shows that London cancer patients gave less positive responses than those from other regions across a range of questions. We therefore investigated the extent to which such differences were statistically significant across the four regions of England used in our survey – North, Midlands & the East, South and London. 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. London patients' responses to these questions are shown in **Figure 73**.

**2** Responses where the variance between London and elsewhere was largest were:

##### Community services

- much more likely to rate care received from GPs as "poor" or "very poor" than other regions (12 per cent versus 6 per cent of patients elsewhere);
- less likely to have received the help they needed for psychological anxiety and distress after discharge (65 per cent versus 77 per cent);
- less likely to say the NHS had met post-hospital health needs "very well" (67 per cent versus 75 per cent elsewhere);

##### Hospital services

- received less written information at diagnosis (57 per cent versus 64 per cent of patients elsewhere);
- much more likely than patients in other regions to have failed to discuss further healthcare needs when desired (17 per cent versus 11 per cent elsewhere);
- less likely to have had "a lot" of confidence and trust in the doctor at the last outpatient appointment (78 per cent versus 85 per cent of patients elsewhere);

##### Both

- much more likely to say their condition worsened while waiting for specialist appointment than other regions (27 per cent versus 19 per cent of patients elsewhere).

**3** In addition, we observed differences between the experiences of patients according to the type of cancer they had. In particular, and as in 2000, patients with prostate cancer responded less positively than patients with other types of cancer. Taking the 80 questions mentioned in paragraph 1, the pattern of responses from patients with prostate cancer compared to other cancer types is shown in **Figure 74**.

**4** Questions where the differences between prostate and other cancer types particularly stood out are shown in **Figure 75**.

**5** In confirming whether statistically significant differences between the experience of men and women cancer patients identified in 2000 persisted in 2004, we found that some had done, as follows:

- a 29 per cent of women with bowel cancer waited longer than one month to be seen by specialist, compared with 26 per cent of men;
- b 32 per cent of men remembered being told how to complain compared to 21 per cent of women; and
- c 28 per cent of men received benefits advice compared to 19 per cent of women.

### 73 Responses to questions by patients from London

Most negative	Second most negative	Second most positive	Most positive
62	6	4	8

### 74 Responses to questions by patients with prostate cancer

Most negative	Second most negative	Second most positive	Most positive
54	14	4	8

6 These differences by region, type of cancer and gender are statistically significant, but may reflect the influence of other factors, rather than a direct link. For example, hypothetically, the less favourable experience of prostate cancer patients could to a greater or lesser extent be due to the fact that some live in the London region, where experiences tend to be worse, rather than be entirely a consequence of having prostate rather than a different type of cancer. Conversely, worse experiences in London might reflect the fact that a number of London patients have prostate cancer, associated with less positive experiences of care.

7 We therefore carried out multivariate analysis to isolate the effect of each variable independent of others. We undertook binary logistic regressions on the original variables. These used the one zero responses given by patients on questions where significant differences across regions, cancer type and gender had been found as dependent variables. The variables that were controlled for were the regions, cancer types and gender relative to London, prostate cancer and women, as well as age of patient.

### 75 Prostate cancer patients responded less positively than patients with other cancers: percentage of patients with prostate and other cancers responding as shown in 2004

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

## Results for Regional Differences: Relationship of Other Regions to London (all results statistically significant to at least 95 per cent confidence level unless otherwise stated)

**8** Question C4: rated care received from GP as poor or very poor.

- Patients in South were 1.49 times more likely not to have answered poor or very poor but this odds ratio not statistically significant.
- Patients in Midlands & East were 1.72 times more likely not to have answered poor or very poor.
- Patients in North were 1.64 times more likely not to have answered poor or very poor.

**9** Question B23: have **not** received enough help for anxiety or depression.

- Patients in South were 1.41 times more likely to have had needs met but this odds ratio is not statistically significant.
- Patients in Midlands & East were 1.56 times more likely to have had needs met but this odds ratio is not statistically significant.
- Patients in North were 2.08 times more likely to have had needs met.

**10** Question B15: whether NHS care after leaving hospital met your needs very well.

- Patients in South were 1.35 times more likely to have had needs met very well.
- Patients in Midlands & East were 1.32 times more likely to have had needs met very well.
- Patients in North were 1.49 times more likely to have had needs met very well.

**11** Question C19: **not** given written or printed information about treatment or condition.

- Patients in South were 1.79 times more likely to have been given the information.
- Patients in Midlands and East were 1.27 times more likely to have been given the information.
- Patients in North were 1.2 times more likely to have been given the information but this odds ratio is not statistically significant.

**12** Question B7: member of staff did **not** discuss before discharge additional help needed to resume usual activities.

- Patients in South were 1.85 times more likely to have had the discussion.
- Patients in Midlands and East were 1.39 times more likely to have had the discussion but this odds ratio is not statistically significant.
- Patients in North were 2.08 times more likely to have had the discussion.

**13** Question D6: Patient had 'a lot' of confidence in doctor seen at outpatients

- Patients in South were 1.55 times more likely to have had a lot of confidence.
- Patients in Midlands and East were 1.37 times more likely to have had a lot of confidence.
- Patients in North were 1.75 times more likely to have had a lot of confidence.

**14** Question C3: Condition worsened while waiting for first appointment with hospital doctor.

- Patients in South were 1.41 times more likely to report condition had not worsened.
- Patients in Midlands and East were 1.69 times more likely to report condition had not worsened.
- Patients in North were 1.43 times more likely to report condition had not worsened.

**15** These results strongly indicate that, for these questions, the experience in London was not as satisfactory as elsewhere, even after allowing for possible type of cancer, gender and age of patient effects.

## Results for Cancer Types: Relationship of Other Cancers to Prostate (all results statistically significant to at least 95 per cent confidence level unless otherwise stated)

**16** Question C2: waiting more than two weeks to see specialist.

- Breast cancer patients were 0.18 times as likely to have waited more than two weeks.
- Lung cancer patients were 0.20 times as likely to have waited more than two weeks.
- Bowel cancer patients were 0.44 times as likely to have waited more than two weeks.

**17** Question A24: side effects of treatment **not** discussed.

- No significant differences between any cancer type.

**18** Question A25: No discussion of how treatment had gone.

- Breast cancer patients were 2.44 times as likely to have had the discussion.
- Lung cancer patients were 2.38 times as likely to have had the discussion.
- Bowel cancer patients were 4.17 times as likely to have had the discussion.

**19** Question A26: Patients would have preferred more information about how treatment had gone.

- Breast cancer patients were 0.55 times as likely to have preferred more information.
- Lung cancer patients were 0.70 times as likely to have preferred more information but this odds ratio is not statistically significant.
- Bowel cancer patients were 0.46 times as likely to have preferred more information.

**20** Question A25: Patients fully understood explanation of how treatment had gone.

- Breast cancer patients were 2.28 times as likely to have fully understood explanation.
- Lung cancer patients were 1.63 times as likely to have fully understood explanation.
- Bowel cancer patients were 2.22 times as likely to have fully understood explanation.

**21** Question A4: Named nurse in charge of care.

- Breast cancer patients were 2.04 times as likely to have a named nurse.
- Lung cancer patients were 1.68 times as likely to have a named nurse.
- Bowel cancer patients were 1.38 times as likely to have a named nurse.

**22** Question B6: Home situation **not** taken into account when discharged from hospital.

- Breast cancer patients were 1.69 times as likely to have had home situation taken into account but this odds ratio is not statistically significant.
- Lung cancer patients were 2.08 times as likely to have had home situation taken into account.
- Bowel cancer patients were 2.5 times as likely to have had home situation taken into account.

**23** Question B10: Patients were given information about support or self-help groups.

- Breast cancer patients were 5.32 times as likely to have had the information.
- Lung cancer patients were 3.19 times as likely to have had the information.
- Bowel cancer patients were 2.33 times as likely to have had the information.

**24** Question D2: Outpatient appointment was cancelled one or more times.

- Breast cancer patients were 0.51 times as likely to have had appointment cancelled.
- Lung cancer patients were 0.49 times as likely to have had appointment cancelled.
- Bowel cancer patients were 0.65 times as likely to have had appointment cancelled.

**25** These results strongly suggest that, for these questions, prostate cancer patients had a less satisfactory experience even after allowing for possible regional, gender and age effects.

## Results for Gender (all results statistically significant to at least 95 per cent confidence level unless otherwise stated)

- 26** When examining gender, we only included patients with cancers that are common to both sexes – in this case bowel and lung cancer.
- 27** Question C2: had waited longer than a month for first appointment with hospital doctor.
- No significant difference for men.
- 28** Question A37: whether patient told how to complain.
- Men were 1.35 times more likely to remember being told than women.
- 29** Question B8: did patient receive benefits advice?
- Men were 1.33 times more likely to receive advice than women.
- 30** These results strongly suggest that, for these questions, women had a less satisfactory experience than men even after allowing for possible regional, type of cancer and age effects.

## Analysis of adverse patient experiences

**31** Our findings indicate that around a fifth of patients reported less positive survey responses in a number of respects. We undertook further analysis to see whether the patients in question formed a group, so that a less positive response in one regard was associated with a less positive response on one or more other aspects. We analysed responses to the following eight questions where the analysis indicated that a substantial number of patients, between about 15 and 20 per cent of the overall sample, had responded negatively. The question references are from our questionnaire available on our web site and covered:

- 590 patients citing Question C2: waiting longer than one month for first appointment with hospital doctor;
- 634 patients citing Question C3: condition got worse;
- 725 patients citing Question A25: partial understanding, did not understand or had no discussion of how treatment had gone;
- 731 patients citing Question A6: did not think there were always enough nurses on duty;
- 758 patients citing Question A8: no confidence in all hospital nurses;

- 627 patients citing Question B2: not given any written or printed information before leaving hospital;
- 579 patients citing Question B6: home situation partly or not taken into account before being sent home; and
- 401 patients citing Question B21: not enough help with overwhelming tiredness.

**32** We looked at which negative responses were potentially linked, based on which issues were most commonly reported in combination with any other negative response. **Figure 76** shows pairwise counts. For example, 590 patients reported negatively on 'waiting more than one month for first appointment to see hospital doctor'; and of these patients 231 of them also reported that 'condition got worse' (and given the pairs of answers in question the table is symmetrical); 121 of those 'waiting more than one month for first appointment to see hospital doctor' also had 'partial or no understanding, or no discussion of how treatment had gone'. Figure 4 also identifies the most common other type of dissatisfaction (or more than one where the scores are close).

**33** Taking the second most reported negative response(s) associated with each question gives the following pairings:

- a** C2 and C3: 'waiting more than one month for first appointment to see hospital doctor' and 'condition got worse';
- b** A25 and A6, A8: 'partial or no understanding, or no discussion of how treatment had gone' and 'did not think there were always enough nurses on duty', 'not confident about all hospital nurses';
- c** A6 and A8: 'did not think there were always enough nurses on duty' and 'not confident about all hospital nurses';
- d** B6 and A25: 'home situation partly or not taken into account before being sent home' and 'partial or no understanding, or no discussion of how treatment had gone'; and
- e** B21 and A25, A8, B6: 'not enough help with overwhelming tiredness' and 'partial or no understanding, or no discussion of how treatment had gone', 'not confident about all hospital nurses', 'home situation partly or not taken into account before being sent home'.

**76** Number of respondents giving one negative response also giving another (most common other negative response(s) shown as\*)

		Number of respondents responding negatively to a particular question also giving negative response to question:							
		Number of respondents dissatisfied		C2	C3	A25	A6	A8	B2
C2	590	-	231*	121	119	115	107	99	72
C3	634	231*	-	129	144	143	121	98	105
A25	725	121	129	-	260*	250*	189	228	143
A6	731	119	144	260	-	371*	157	173	129
A8	758	115	143	250	371*	-	181	199	141
B2	627	107	121	189	157	181	-	200	118
B6	579	99	98	228*	173	199	200	-	137
B21	401	72	105	143*	129	141*	118	137*	-

Source: NAO analysis

Source: NAO analysis

**NOTE**

\* most common other negative response(s)

Question Key:

C2: Waiting more than 1 month to see hospital doctor

C3: Condition got worse

A25: Partial or no understanding, or no discussion of how treatment had gone

A6: Did not think there were always enough nurses on duty

A8: Not confident about all hospital nurses

B2: Not given any written or printed information before being sent home

B6: Home situation only partly or not taken into account before being sent home

B21: Not enough help with overwhelming tiredness

**34** By inspection, this in turn suggests linked factors of dissatisfaction:

- a** C2/C3: 'waiting more than one month for first appointment to see hospital doctor' and 'condition got worse'; and
- b** A25/ A6/ A8/ B6/ B21: 'partial or no understanding, or no discussion of how treatment had gone', 'did not think there were always enough nurses on duty', 'not having confidence in all hospital nurses', 'home situation partly or not taken into account before being sent home', 'not enough help with overwhelming tiredness'.

**35** These finding are consistent with the results of the factor analysis in Appendix 2. In particular, the cluster identified here, C2/C3 is the same as Dimension 10 Access to Care - Waiting Times, while the A25/A6/A8 grouping picks a number of elements within Dimensions 1 and 2 of the factor analysis, 'First Treatment, Respect, Trust and Hospital Management' and 'Understanding of Diagnosis and Treatment'.

**36** We then went on to examine how many of patients who had responded to all eight questions and were dissatisfied in one respect, were dissatisfied in addition in one other aspect, two others and so on. Patients who did not respond either way on any question within the eight above were excluded from the analysis.

**37** The results are shown in **Figure 77**. In total 997 patients reported at least one negative response across the eight questions considered. The table shows that of the 997 respondents giving at least one negative response, 361 respondents reported only one out of a possible eight. A further 277 respondents reported two negative elements; a further 165 reported three; and so on. Only two respondents gave negative responses to all eight elements considered.

**38** Overall, three quarters of respondents who answered all 8 questions reported negatively to two or less questions. While no negative responses would be desirable, this is unlikely to be achievable. In fact, 30 per cent of respondents had no negative responses to these questions. One quarter of respondents who answered all 8 questions gave negative responses to 3 or more different questions (one third of those who gave at least one negative response). These 359 patients represented about 8 per cent of the total sample of 4323 respondents. Seventy nine per cent of them were over 50 years of age, compared with 85 per cent of all respondents.

**39** The characteristics of this group of multiple complainants are shown in **Figure 78** in relative terms, measured by the proportion of the group of 359 patients in a category, compared to the proportion of all 4323 responding patients in the same category. This shows if the patients with multiple negative responses are over-represented, (a figure in excess of 1), or under-represented, (a figure less than 1), in respect of the various characteristics compared to our sample as a whole. The results indicate that bowel and prostate cancer patients are over-represented and breast and lung cancer patients under-represented in the group reporting negatively on three or more occasions compared to all respondents in our survey. This suggests that although prostate cancer patients generally produced the most negative responses (paragraph 3 of the Appendix), bowel cancer patients are prone to have more serious negative experiences when they do occur. There is also a marked over-representation of patients from London.

**40** We also looked at which complaints were most commonly cited by patients expressing three or more elements of dissatisfaction, as shown in **Figure 79**. It shows that the most prevalent elements were 'partial or no understanding, or no discussion of how treatment had gone', 'always not enough nurses on duty' and 'not having confidence in all hospital nurses'.

## 77 Frequency of patients reporting multiple negative responses

Number of negative responses given to the 8 questions selected	Number of respondents giving this many negative responses	Per cent of all respondents reporting this many negative elements of the experience	Percentage of all those reporting one or more negative elements of the experience who reported this number of negative responses
0	405	29	-
1	361	25	36
2	277	20	28
3	165	12	17
4	98	7	10
5	53	4	5
6	29	2	3
7	12	1	1
8	2	0	0
Total	1402	100 per cent	100 per cent

Source: NAO analysis

## 78 Representation of patients with three or more negative responses relative to the sample as a whole

Characteristic	Percentage of 359 respondents giving 3 or more negative responses	Percentage of all respondents	Percentage of 359 patients giving 3 or more negative responses compared to percentage of those with a given characteristic in the sample as a whole of 4323 patients*
Aged over 50	78.81	84.65	0.93
Male	36.16	39	0.93
London	17.55	14.1	1.25
Midlands and East	26.46	29.3	0.9
North	40.67	40.9	0.99
South	15.32	15.7	0.97
Breast cancer	40.95	46.9	0.87
Bowel cancer	35.1	27.8	1.26
Lung cancer	9.19	11.2	0.82
Prostate cancer	14.76	14.1	1.05

Source: NAO analysis

### NOTE

\*Not all patients indicated their age or their gender; therefore the numbers above are calculated excluding the cases for which no information was provided.

Data on age group was provided for 354 cases (as opposed to 359) for the sub-sample of dissatisfied patients in 3 or more elements and 4092 (as opposed to 4323) overall.

Data on gender was provided for 354 cases (as opposed to 359) for the sub-sample of dissatisfied patients in 3 or more elements and 4084 (as opposed to 4323) overall.

## 79 Concerns of patients who reported three or more negative responses

Negative response	Number expressing 3 or more negative responses	Proportion expressing 3 or more negative responses %
C2: Waiting longer than one month for first appointment with hospital doctor	140	10
C3: Condition got worse	172	12
A25: Partial or no understanding, or no discussion of how treatment had gone	199	14
A6: Always not enough nurses on duty	197	14
A8: Not confident about all hospital nurses	214	15
B2: Not given written or printed information before leaving hospital	137	10
B6: Home situation not taken into account before being sent home	183	13
B21: Not enough help with overwhelming tiredness	184	13

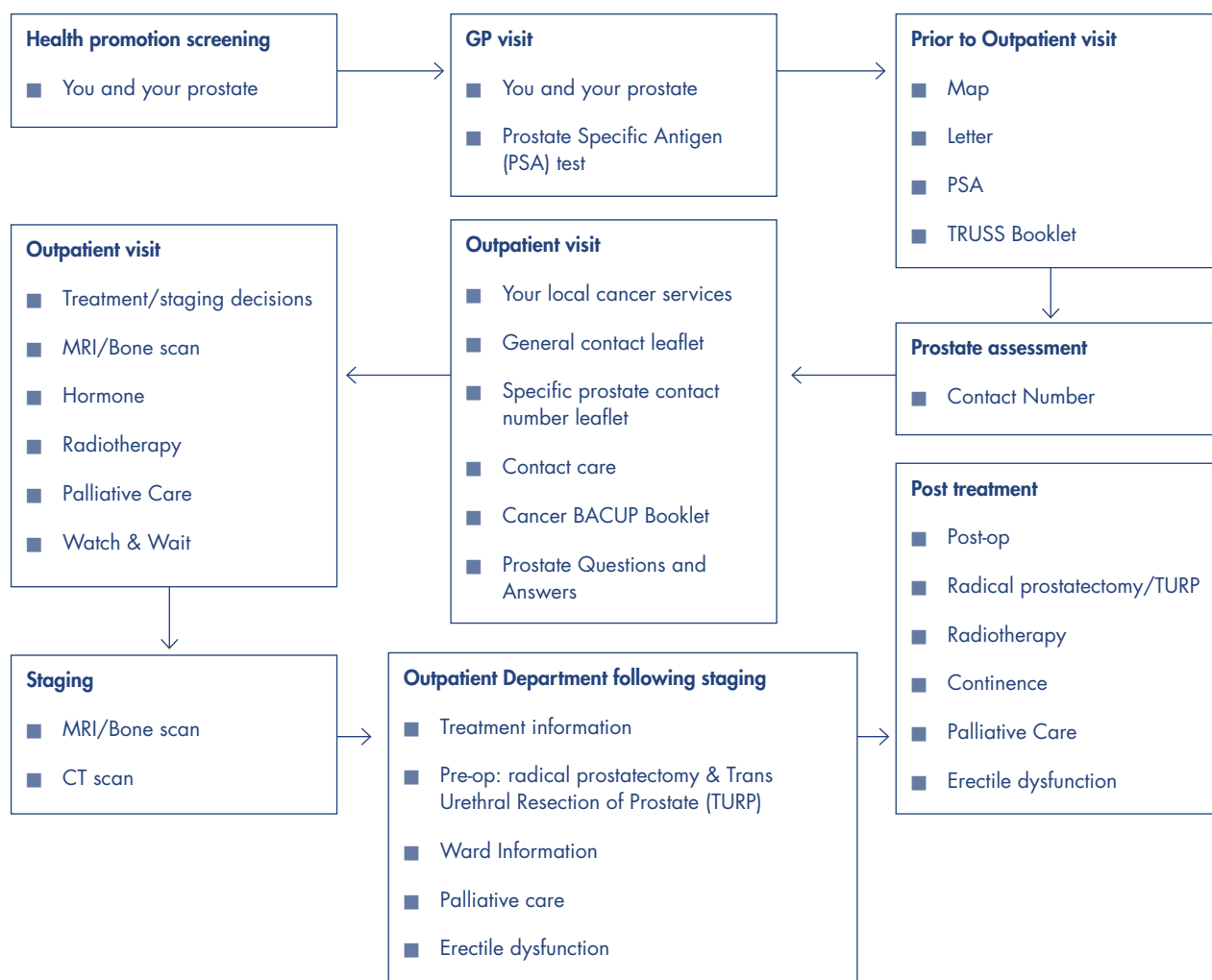
## APPENDIX 4

### The cancer patient information pathway

**1** The Modernisation Agency Cancer Service Collaborative 'Improvement Partnership' operates a Patient Experience Programme with the objective of ensuring that patients receive high quality information, tailored to their individual needs, at appropriate points in the care pathway.

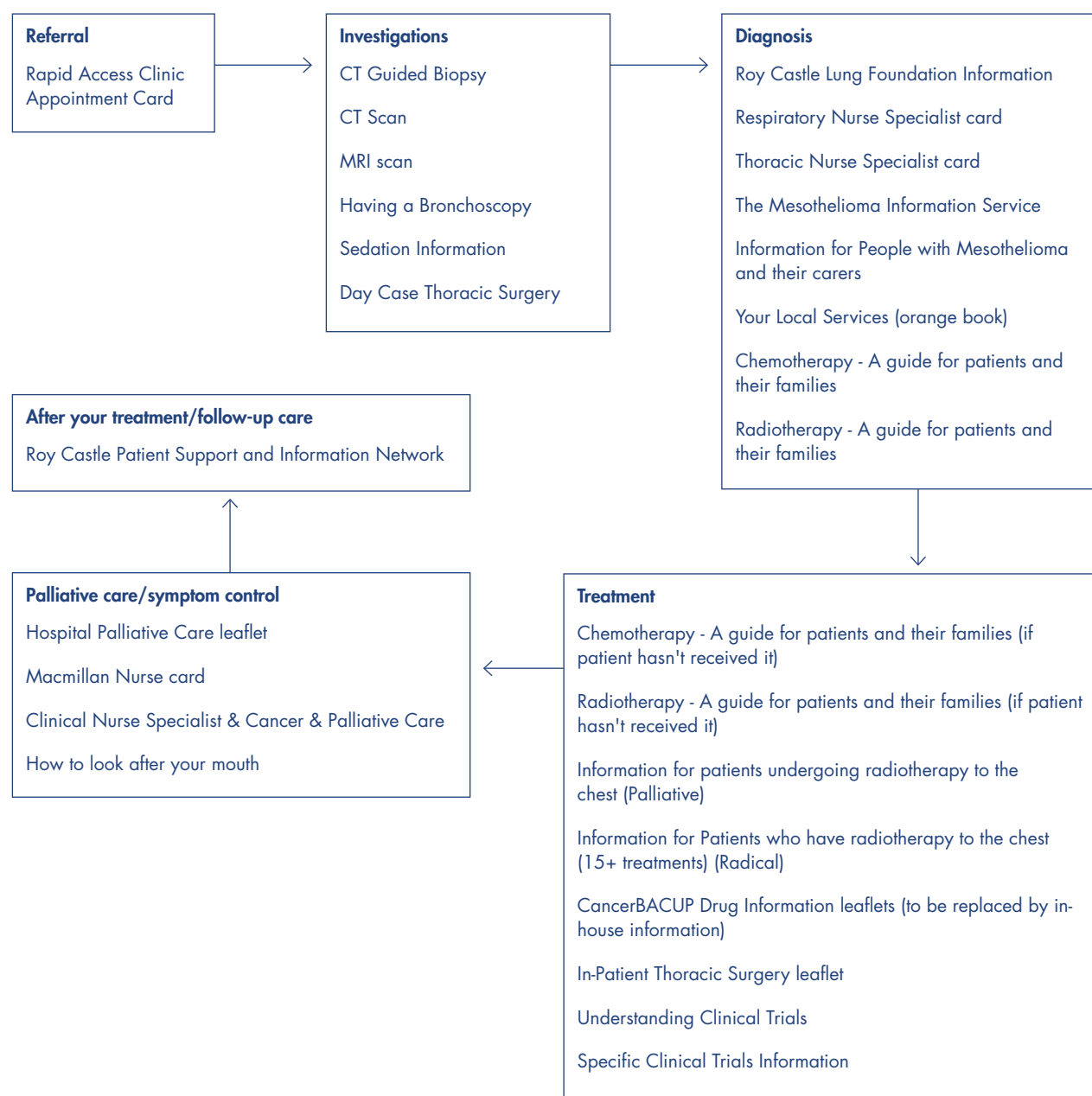
**2** The National Patient Experience Team is currently supporting all Cancer Networks to work out what to offer to patients and how to make it happen – to agree and introduce sustainable patient information protocols – for at least two tumour types across their Networks. A key part of this is to map the information needs at key stages in the patient journey. Below (**Figures 80 and 81**) are two examples of the patient information needs for prostate and lung cancer, as mapped out by the Leicester Cancer Centre.

#### 80 Prostate cancer patient information pathway



Source: Modernisation Agency Cancer Service Collaborative 'Improvement Partnership' Patient and Carer Experience Project

# 81 Lung cancer patient information pathway



Source: NHS Modernisation Agency Cancer Services Collaborative 'Improvement Partnership' Patient and Carer Experience Project

## APPENDIX 5

### Transcript of Patient Interviews on the Video Disks provided with this report in DVD and Windows/Mac compatible format

We asked five volunteers who had originally taken part in our survey for the Report to talk about the experiences they had had during their illness. Their comments cover the diagnosis and treatment phases of the illness and also their experiences following discharge from hospital. The views expressed are relevant to the content of the Report but are not part of the formal audit findings. The intention is to provide personal insights into the subject matter of the Report, additional to the statistical and other analysis. The National Audit Office expresses its considerable thanks and gratitude to the people who took part. Interviewing was carried out in February 2005 by Origin ID.

#### Diagnosis

**Andrew:** Hello my name is Andrew, I'm a 57 year old widower, and I've been dealing with a prostate condition since 1995.

**Carol:** I'm Carol Adams, and two years ago I was diagnosed with colon cancer, which then subsequently spread, to my liver.

**Judith:** My name's Judith Broadbent. I've had a number of illnesses and I've had 17 operations so there's, I've got quite a history of things. But probably the most traumatic illnesses that stick in my memory most are that I had breast cancer twice.

**David:** My name is David Rixon. I'm 67 years old, retired. I was in the meat trade for many years. I had no symptoms. I had read a lot of publicity about prostate trouble for men of my age and went along for a check up.

**Barbara:** I'm Barbara Alexander and about 18 months ago I was diagnosed with bowel cancer.

#### How were you told the news?

**Andrew:** I was on my own when I had the news broken to me, I was sort of semi-expecting it because I had the two sets of biopsies.

**Carol:** By that time I was with a colon specialist, told me the probability although they didn't know until they operated. He then told me as arranged actually he telephoned me because I wanted to know before the Easter bank holiday and I had a very sympathetic phone call at an arranged time when he'd been able to analyse the matter just before Easter. So it was done in a way that was agreed.

## How were you told the news? continued...

**Barbara:** I went to a consultation at the hospital and I was told but I was well prepared for it because in the end it was confirmation of what people had thought for quite some time really. So it was fine.

**Judith:** You know immediately it's bad news when a huge number of people walk in to the room so I knew immediately it was bad news - and that it was breast cancer again and I had to have a mastectomy.

## How did you cope?

**Barbara:** I coped in two ways. I coped in the sensible way in that I tried to stay rational and focused and ask questions. But then there was an irrational response which made me think that I was going to be dead in two weeks and all the things I've got to do before then. There were two sort of strands to it.

**David:** I never thought of it as terminal I just thought it was another nuisance of getting older. They did tell me that it was borderline and I read that if it's treated early, the old cliché is that more people die with it than die of it. I hope that will be the case.

**Judith:** The first time I was told I had breast cancer I was very, very upset because I was a lot younger, I was ten years younger and I assumed I was going to die. I just didn't know anything about, I didn't know anything about cancer it was a bolt from the blue first time. Second time I was not surprised because when you get a lump it seems its cancer.

**Andrew:** First of all when you are told you have a cancer I think you realise that you are a mortal being, and that is quite a big thing to take on you go through life and you think you've got no problems, but coping with that from an emotional point of view, as I say I think I became proactive, that is how I dealt with it, let's get on and deal with it, and let's find out as much as I can about the condition and the ways forward to treat it and that's how I personally coped with it.

**Carol:** I managed to be extremely positive. I wasn't devastated. Or saw it as something to be as a challenge to be dealt with and to try and overcome it and to draw on all the resources available to give it my best shot.

## How did you deal with telling family & friends?

**David:** The family obviously knew that I was going, I didn't keep any secrets. You know, we're a close family.

**Carol:** I told everybody very honestly at that stage what had happened. Although at that stage I hoped very much that I'd recover and be 100 % fit afterwards. So yes I told people and that brought enormous support.

**Barbara:** That was the most difficult for me. I had to tell them before hand because leading up to the diagnosis. I'd needed help because certain tests I'd needed to have I had to have, I had to be looked after overnight afterwards so I couldn't cope on my own.

**Andrew:** My mother was very ill and very sensitive and I'd just lost my brother at the time as well through another illness and I couldn't really break the news to my mother directly and so I had to confide in my other relatives, my sister-in-law and other people were aware but I didn't want to trouble them too much because of all the other issues that were taking place at the time. It was quite difficult but I did have the support of a close friend.

## What support did you get from family & friends?

**Barbara:** I had excellent support from both my family and friends.

**David:** We're not a particularly emotional lot. Support was always there we didn't discuss it very much – we were more worried about not missing the appointment.

**Carol:** The phone never stopped ringing, people visited, work colleagues were fantastic, my work was very good and supportive in my absence. And people were wonderful actually.

## In Hospital

Please describe your first experience of treatment in hospital.

**Judith:** I have found my experiences as a patient in hospital have always been very satisfactory. I've never had any complaints or any particular questions about surgery or anything. The worst, the thing I found most difficult about being hospital is that everything happened so very, very slowly. So the doctors come around at 8:30 in the morning and then almost nothing else happens all day.

**Barbara:** As an inpatient that's when I went in for surgery and I was very well prepared for that and I went in very calmly and I had confidence in the people and in the whole hospital really so it was very positive. In so far as it could be positive.

**Carol:** I was part of a ward of many, many women waiting for scans for all sorts of aches and pains and yet if someone had put together the history of what had happened to me and the tests that had been done and the nature of my pain I think I should have been with a colon specialist much earlier. There doesn't seem to be a good system on admission to hospital for streamlining getting you to the person who can put together the various symptoms.

**Andrew:** When I went to hospital I was sort of admitted by a series of locum doctors or agency staff, and obviously they weren't aware of the history that I had, and so that was a bit difficult to understand that all that they were doing was actually admitting you to the hospital and doing the necessary tests, but I was reassured a bit later on when I actually did see the consultant, and he talked me through the actual procedure again that I was going to be involved in.

Can you give examples of how you were informed and involved in what was happening?

**Barbara:** Everything was explained to me and I was allowed to ask questions which were very fully answered.

**Andrew:** Actually I had to make big decisions at the time, because I was given the option of treatments and obviously the surgeon wants to carry out surgical work, the radiologist wants to do radiotherapy, and so I have to be, I was involved in that decision process. Luckily enough I sort of had enough control, because another factor when you are told that you've got cancer is that you feel a bit out of control.

**Carol:** Once I was in hospital all of the discussion and information sharing and all of the treatment was excellent. Once we got to a diagnosis I was made fully aware of all of the issues, the likelihood of treatment. I was asked if I had any questions.

## What support did you get and what was most helpful to you?

**David:** I didn't really feel that I needed support in the hospital. It was when you go in there you couldn't, I always thought this with the National Health, minor things you have difficulties but when you've got something seriously wrong I found them extremely good.

**Andrew:** One particular nurse that sort of did take an interest was an old trained National Health nurse who was actually working as an agency nurse, but I did have some kind of bond with her, and I managed to talk of the emotional side of the actual illness and I found that she provided quite a good amount of support at that time for what was happening, and she had the experience so she knew exactly what the situation was with being a patient having this treatment.

**Judith:** The second time that I had breast cancer I was with a breast support nurse. So she was someone that I felt that I could spend more time with because one thing that you never feel that anyone's got a lot of, is time and especially time that you can spend with your consultant is extremely minimal. The breast care nurse you felt that you could spend time with her and that she would understand when you were upset and so I'd splurge on about my concerns.

**Barbara:** The nursing staff were very expert and very attentive. They were very good and I felt I was being monitored the whole time. There was also sort of extra support because with my particular surgery I have a colostomy and I also had a pre-existing mobility problem so I needed a lot of physio and all that support was available.

## How were you made aware of possible side effects of treatment?

**Carol:** I've had all the possible side effects explained to me not only by the oncologist but by the nurses who give chemotherapy. I found all of that information and discussion very, very helpful, very well informed.

**Andrew:** The actual side effects of the treatment I got most information for that from the actual hospital leaflets.

**Judith:** I was made aware of the side effects of my treatment by probably leaflets and explanations and by myself using the Internet and having a look at the drugs I was being given there or the procedures.

**Barbara:** The side effects and what I might expect as a result of the treatments were very well explained beforehand. Some I hadn't anticipated and one in particular which was the result of not eating and drinking for a very long time. But otherwise it went more or less as I expected and there weren't any nasty surprises.

## How much did you understand about your condition and treatment options?

**David:** I understood as much as a layman could I think. I didn't really want to go into all the medical details as far as I was aware there was a small growth.

**Carol:** I had everything fully explained to me. Ever since the diagnosis I've found information is very good.

**Barbara:** I did understand all the implications I think because I'd thought about it a lot I'd researched it beforehand I'd looked on the Internet all those things. And people answered my questions and the thing that I most appreciated was that I was allowed to weigh up the options. They put them very fairly before me. I mean there's a limit to the choice you have in those circumstances but I did feel that I was involved and to some extent in control.

**Andrew:** At the time I fully understood the actual treatments that were available and the actual treatment that I was undertaking and I was able to discuss that quite in detail with the actual consultants at the time.

**Judith:** You're told lots of pros and cons but you are not directed into which decision to make. And definitely the first time I had breast cancer I really wished someone would just decide for me and I really wanted my consultants to say I think you should have a mastectomy or I think you should have radiotherapy, no one, no one did, so I had to make that decision.

## Did you feel your views were taken into account?

**David:** I can say that I feel my views were taken into consideration particularly by the top man and all his deputies they were all extremely good. I'm sure if I'd said I don't want this breaking therapy I don't fancy radio-activity. In fact it's a bit of a joke in the family, radioactive keep away that was afterwards. But they went to great lengths to explain it.

**Barbara:** My views were taken into account because I was asked and I agreed to be part of a national clinical trial. And so I was given a lot of information and again I had consulted the Internet and I was allowed to choose that without any influence one way or the other.

**Andrew:** I did try to insist on one type of treatment which I thought was a better option and I had to go back and have a second test to see whether a course of tablets had allowed the actual prostate to shrink to allow this treatment to be carried out. So I sort of managed to achieve that and have the treatment that I particularly wanted at the time.

**Judith:** I always felt that my feelings were taken into account yes I think they have been very good at explaining things to me.

### How involved were family and friends?

**Barbara:** When I was in hospital my family and friends were involved as much as I wanted them to be and as much as they needed to be. They were allowed to visit. People spoke to them and explained to them but actually most of the time I was able to explain to them myself.

**David:** I'm inclined to think that if I'm happy with what's happening to me I'd rather leave it to the people who know what they're doing and don't ask too many questions. I would have done if I'd thought that things were going wrong. But the attention was very good if you wanted painkiller or anything like that it was always there. And it was a self contained little room even a private patient couldn't do better.

### Was there pain? How did hospital staff help?

**Carol:** I did have acute pain after the operations. There are some difficult moments when you need pain relief in the middle of the night and the on-call doctor has to be found in order to sign the prescription. And I have had experience of having to wait several hours for that. That seems to me a system that could be improved in hospitals. I wasn't in life-threatening pain I was just in acute postoperative pain.

**Barbara:** The pain control was something, which I hadn't anticipated. It was a very long time since I'd had major surgery like 50 years before I'd had major surgery. And this time I experienced really very little pain. It was very carefully controlled and that was all planned and there was a special pain control nurse who when it didn't quite work was summoned and everything was arranged yes it was put in order.

## Discharge and Community Care

How did you feel about leaving hospital and going home?

**Carol:** In terms of leaving hospital I've never been able to wait to get out of hospital. I was always very fit and very ready to leave hospital. I found that process very good actually after three operations. As soon as I was fit and able to manage food I was sent home I was never kept in hospital an hour longer than I needed to be. I had a very good recovery. So I found that very satisfactory.

**Judith:** I've always been delighted to leave hospital and go home it's never been a concern to me. I can always manage by myself pottering about. Friends and neighbours have done bits of shopping for me.

**Andrew:** Leaving hospital was okay in fact I couldn't wait to get out to have a good nights rest really because it's very noisy in hospitals and it was very nice to be discharged. Although, the discharge process involved quite a lot of delays and waiting for the actual consultant to come around and allow you to go home. But apart from that that was fairly straight forward and I was taken home and supported by friends and family at the time.

**Barbara:** I felt fairly confident because they had kept me in hospital probably 3 or 4 days than is usual or probably longer than they planned to do because I needed a bit more care I needed more time to get mobile than I think they probably realised. And coming home then I had one of my family came and stayed with me for a week and it went well. But I did need a lot of care when I came home there was very little I could do for myself.

Did anyone inform you about support groups?

**Carol:** In terms of support after the operation I had a lot of support afterwards, complementary therapies, access to nurses but the thing I've most valued is the relationship with my GP which has been about total availability and willingness to speak to me and be helpful at any time.

**Andrew:** I wasn't informed of any real support groups and I think that's quite important to be able to talk to other people in the same situation I think that it's really important now in hindsight. You really get so much from talking to people, or I do now, who have had this particular problem. And at the time there was no information or very little information or very little information about support groups.

**Judith:** I'm sure there are breast cancer support groups but I wouldn't want to join one but I do like knowing that there's a breast care nurse that I can ring if I've got any worries.

## At home did you get any support?

**Barbara:** When I came home there was follow-up support from district nurses who came often. And also for the stoma support nurses whom I'm still in touch with I have a telephone line and they give me ongoing advice, advice about new products because that something I have to live with all my life so that very valuable.

**David:** Talking about support afterwards. I was informed about support groups but all of us are a rather solitary people and I'm sure if we'd ever wanted it we could have gone to it but and financially fortunately we're okay but they were mentioned and we could have followed up if we'd needed to.

## Did you find anything out about financial benefits?

**Judith:** Financial benefits have never been applicable to me. I've always just been off sick for a while and my employers have always paid sick benefit and then I've gone back to work full time with reduced hours and then full time.

**Andrew:** I wasn't aware of any financial benefits at all and I've actually, because of the information that I've received from the actual prostate cancer charity I've made a donation to the prostate cancer charity because they provide excellent information booklets. But I've not been aware of any financial support at all for my condition.

**Barbara:** Financial benefits I haven't looked into. I shouldn't think I'm eligible because of my circumstances. But I'm sure that if I had needed it and if I had asked the information would have been available.

**Carol:** In terms of financial benefits fortunately I've been in a situation where I haven't had any financial difficulties so it hasn't been an issue I've had to look into at all.

## How did you cope with life back at home?

**David:** The problems we faced coming back home. The main one is passing water, whether that's to do with the prostate or whether it's to do with age I don't know. But you go for a check up and you usually end up talking to a particularly glamorous lady doctor with a particular one the first time talking about penile malfunctions! At first it's very embarrassing but after a bit she's not embarrassed so why should I be and you tick off the list.

**Barbara:** When I got home I recovered quite slowly physically but I'd been warned that it would take 6 months. And the help I needed I had. I mean I live in a place, which is accessible which I didn't get a feeling of confinement so much, which I might have done. It's difficult adjusting to your changed physical state and that something that you need to come to terms with and I guess that takes a long time.

## How did you cope with life back at home? continued...

**Andrew:** Life back at home. When I came home I did have a problem after the actual procedure, which I was aware, could happen and did happen. I had to go back to the accident and emergency a week or so after the actual procedure, which happens to a small number of people. But apart from that, things have been going well and I've been managing the situation.

**Judith:** I think because I had a child to look after and no one else at home that always made me try and get myself as good as possible quick as possible and not be too maudlin about things and certainly not to be despairing because that would have been the last thing that he'd of needed...

## What would you say to someone who has just been told they have the same condition as you?

**Carol:** What I've found quite interesting is talking to people friends who've recently been diagnosed with cancer and recognising them being at the stage I was in the beginning when you sort of thought you were going to marshal your troops and beat it. And just thinking that there's another stage of recognising that it actually can control you, you don't control it. And to many people maybe that is hard and perhaps it's that longer-term support that cancer sufferers need.

**Barbara:** To anyone else who might be in the same position I'd think I'd say that you should try to inform yourself to get as much information as you can and to review the options. And if possible not to fret too much about what are not options anymore. That's hard to do but I think the NHS has responded very well to me in that respect and that's helped me to cope with the whole experience.

**David:** If I was told that somebody had a condition I would say well get on don't hesitate because there's bound to be delays of one sort or another. My own operation was put back a couple of times and the warning is not to leave it too late.

**Judith:** I think if someone was diagnosed with those conditions they would probably have a fairly bleak outlook. I would be encouraging and I would tell them what to expect. But what you can't do is everyone's experience is different, everyone's experience of the same illness is different, peoples' prognosis' are different.

**Andrew:** I'd say talk to people. Talk to as many people as you can and find out as much information, there's lots of information available. Find out as much information as you can.

**Carol:** I think I would encourage them to really do all they can to overcome it and to believe that it can be cured but they mustn't start thinking in terms of this being fatal and how long have I got? That cancer these days is a long journey, there are new treatments coming on-line. And particularly if somebody's at the start of that journey they'll have different drugs and treatments to the ones I've had over the last two years. So I think I would encourage them to be optimistic but also to be realistic about it and to accept that you do have to have a different mindset about life.