



House of Commons
Committee of Public Accounts

**Department of Health:
Tackling cancer:
improving the patient
journey**

**Nineteenth Report of
Session 2005–06**

*Report, together with formal minutes,
oral and written evidence*

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The Committee of Public Accounts

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Contents

Report	<i>Page</i>
Summary	3
Conclusions and recommendations	4
1 Access to specialist care and diagnosis	7
2 Support offered to patients during and after treatment	9
3 Differences in patients' experiences	13
Formal minutes	16
Witnesses	17
List of written evidence	17
List of Reports from the Committee of Public Accounts Session 2005–06	18

Summary

In 1999–2000 the Department of Health surveyed 65,000 cancer patients across all NHS Trusts in England. The Department identified areas for improvement, but found generally high levels of patient satisfaction in most areas, including dignity, privacy and respect. When published in 2002, the survey provided a baseline against which to measure changes in cancer patient experiences. Since this survey was carried out, additional funding of more than £1 billion has been provided for cancer services and the Department of Health and the NHS have introduced a range of measures to improve access. Guidelines have also been published by the National Institute for Clinical Excellence on the optimal treatment of breast cancer (1996), bowel cancer (1997), lung cancer (1999), and prostate cancer (as part of the urological cancer guidelines in 2002). The NHS Cancer Plan has also been issued governing what needs to be done to make the patient experience as acceptable as possible.¹

To gauge progress made in the four years since the introduction of the Cancer Plan, the National Audit Office carried out a national follow up survey of cancer patients in early 2004² involving 4,300 patients in 49 NHS Trusts with the four commonest cancers: breast, lung, bowel and prostate cancer. Overall, patients were broadly positive about their experiences; some progress had been made in most aspects of the patient experience since 2000, though less so for prostate cancer patients. In addition, both prostate cancer patients and cancer patients in London as a whole reported a worse experience than other cancer patients.

Other elements of the patient experience were still not as good as they might be, regardless of cancer type, such as communicating information, symptom relief and the lack of options for some patients in their last days. In particular, terminally ill cancer patients were often not made aware of non-means tested disability benefits that they could have claimed to alleviate financial hardship, estimated by Macmillan Cancer Relief at over £100 million in a six month period.

The main focus for the Department and local cancer networks over the past four years has been to improve cancer supportive and palliative care in line with the National Institute for Clinical Excellence guidance. Hospice services and palliative care have received additional funding since 2003–04, though patients who wished to die at home or in a hospice were still more likely to die in hospital.

1 2nd Report from the Committee of Public Accounts, *Tackling cancer: saving more lives* (HC 166, Session 2004–05); C&AG's Report, *The NHS Cancer Plan* (HC 343, Session 2004–05)

2 C&AG's Report, *Tackling Cancer: Improving the patient journey* (HC 288, Session 2004–05)

Conclusions and recommendations

- 1. While referral times have improved since 2000, 40% of patients eventually diagnosed with cancer still waited more than two weeks to see a specialist following referral by their GP.** Delays heighten patient anxiety and may have adverse consequences for the course of the disease. 80% of patients with suspected breast cancer are currently seen within two weeks, and this is the standard to which cancer networks should aspire for all patients with suspected major cancers.
- 2. More than a quarter of patients with bowel cancer waited more than a month after being referred by their GP to see a specialist, during which time around 30% reported a deterioration in their condition.** The Department should work with GPs to reduce waiting times for referral to a specialist by improving the ability of GPs to identify symptomatic patients promptly.
- 3. Only 34% of patients with prostate cancer received information on relevant cancer support or self-help groups who could provide information and support, compared with 70% of breast cancer patients.** Consultants, specialist nursing staff and the Department of Health should promote access to national and local dedicated support and self-help networks for those suffering from cancer, working in partnership with existing groups to strengthen their networks. Formal assessments between specialist nursing staff and the patient should include a check that the patient has been made aware of national and local support and self-help groups.
- 4. Providing specialist care for patients with prostate cancer has been lower priority than for other major cancers, such as breast cancer, even though prostate cancer is one of the most common cancers, killing some 10,000 men each year in England.** Informed by the outcome of the 2005 peer review exercise across all cancer services, the National Cancer Director should publish an in-depth report on the standard of prostate services around England as well as the reasons for deficiencies, and work with cancer networks to establish and implement action plans for improvements where there are problems.
- 5. Just 10% of patients reported that they had been given a record of significant matters discussed during diagnosis and at key stages during their treatment.** The Department should act upon advice recently published by the National Institute for Clinical Excellence that patients should be offered a record of matters discussed with clinicians, so as to avoid needless anxiety and uncertainty.
- 6. A fifth of patients had either not discussed or not fully understood the potential pain and side effects associated with their treatment and possible alternative or complementary treatments.** All cancer patients should receive a formal assessment by their clinical nursing specialist and consultant of the support needed to manage the pain, stress and anxiety caused by their cancer.
- 7. The regional distribution of hospice and specialist palliative care bears no relationship to need or population levels, with 60% less inpatient beds per thousand cancer deaths in the Midlands and East region than in London.** In part, these inequalities are due to the general shortage of specialist nursing staff and

unfilled consultant posts. The Department should set national recruitment targets and measure progress towards implementing National Institute for Clinical Excellence guidance on improving supportive and palliative care for adults with cancer. Regional and national progress summaries should be published.

8. **London cancer patients were less positive than those in other regions about the quality of service they had received, even though London had the same or higher levels of expenditure and range of services available, and clinical outcomes in London compared favourably in terms of survival rates.** The London Strategic Health Authorities should research the reasons for patients' poorer perceptions of cancer care in London and produce an action plan based on the results to address shortcomings.
9. **Over three quarters of patients were not given information on financial benefits by the NHS or others, but nearly half of those not given the information would have welcomed such advice.** Research carried out for Macmillan Cancer Relief in 2004 estimated that, in 2001, terminally ill cancer patients with six months or less to live failed to claim benefits worth £106 million in six months. In partnership with the Department for Work and Pensions, cancer support groups and other voluntary bodies, healthcare professionals should receive training designed to give them an adequate knowledge of the benefits system such that they can advise patients at all stages in their treatment, including the terminally ill.
10. **Whilst best practice has been developed to improve support for dying cancer patients and their families, it has not yet been widely adopted.** To improve the quality and choice of end of life care, cancer networks should work with Primary Care Trusts and others to identify and break down the barriers preventing wider adoption of best practice, and the Department of Health should update earlier research with terminally ill patients to monitor the impact.
11. **NHS staff and cancer support groups continue to provide dedicated and professional treatment, advice and support services which are highly valued by cancer patients, their families and friends, as evidenced by the positive responses to key measures of patient satisfaction in Figure 1.** The Committee also wishes to pay tribute to the outstanding contribution made by the volunteers and staff who work in hospices and cancer advisory and support groups.

Figure 1: Key items from surveys of cancer patients' experience of treatment and care comparison between 2000 and 2004

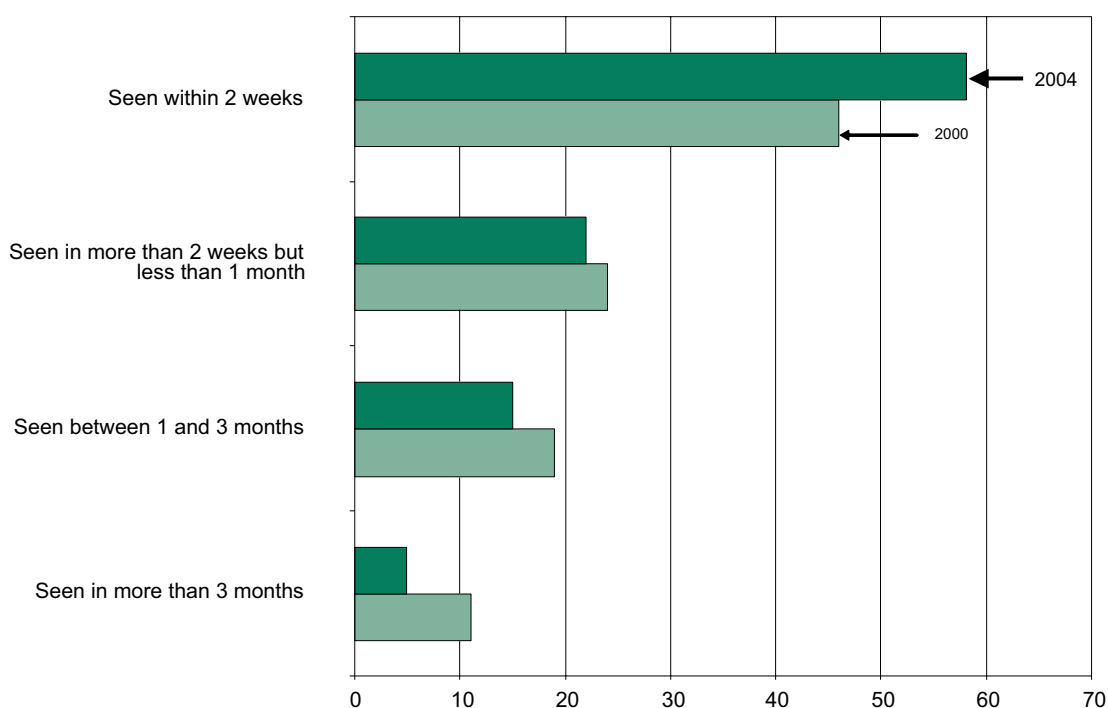
	2000 %	2004 %
Patients did not perceive a worsening in their condition while waiting to see specialist	74	80
Patients told what was wrong with them with sufficient sensitivity and care (n/s)	94	94
Doctors or nurses discussed the purposes of treatment with patient and patients completely understood the explanation	82	86
Patients found doctors' explanation of condition, treatment or tests very easy to understand	62	68
Patients 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 patients at discharge covered all issues	*	96
Patient told about support or self-help groups (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		
Items are drawn from representative questions for each "theme" within the 2004 NAO Cancer Patient Survey		
For the items marked (n/s) the year-on-year change is not statistically significant		
Questions marked * not asked in 2000		

Source: National Audit Office

1 Access to specialist care and diagnosis

1. Whilst the speed with which patients were seen by a specialist following referral had improved since 2000, too many patients still experienced delay between referral and consultation in 2004. Overall, whilst 99% of patients referred urgently by their GP saw a specialist within two weeks, approximately 40% of people ultimately diagnosed with cancer were not referred urgently and were not seen by a specialist within two weeks of referral, and one fifth waited for one month or more (**Figure 2**). 70% of patients with breast cancer were seen within two weeks, but only 32% of prostate cancer patients.³ The Department saw the target for all patients to be seen by a specialist within a maximum 18 weeks from referral as a key driver for service improvement.⁴

Figure 2: Waiting times between referral by GP and being seen by a specialist had improved since 2000 but some patients still waited more than two weeks



Source: National Audit Office

2. Around a third of cancer patients did not find doctors' explanations of their condition, treatment or tests very easy to understand. Given the complexities of most types of cancer, and the range of tests and treatments available, clinicians needed good communication skills to break bad news with appropriate sensitivity and care. New guidance published by the National Institute for Clinical Excellence in March 2004⁵ recommended that patients should be offered a record of significant matters discussed with consultants and clinicians. At the time of the NAO survey of cancer patients, just 10% of patients received a written or

³ C&AG's Report, Figure 5

⁴ Qq 1-2

⁵ *Improving supportive and palliative care for adults*, National Institute for Clinical Excellence (2004)

audio record of their diagnosis,⁶ though a randomised control trial in Australia had shown that writing to the patient was beneficial. Whilst a tangible record in the form of a letter may be appropriate for some patients, other types of record, such as a recording of the interview, should be considered for those with poor literacy and language skills.⁷

3. Patients with bowel cancer, although generally satisfied with the care that they received, frequently expressed dissatisfaction with the delay between being referred by their GP and seeing a specialist. Difficulties in correctly identifying the symptoms of bowel cancer delay prompt access to specialist care for patients with the disease, undermining patient confidence and causing anxiety. More than a quarter of patients diagnosed by their GP as possibly suffering from bowel cancer waited more than one month to be seen by a specialist and in 2004 30% of bowel cancer patients reported a deterioration in their condition while waiting, compared to 16% for other cancers.⁸ Research commissioned by the Department should assist GPs to correctly identify symptoms suggestive of bowel cancer.⁹

4. With the phased roll-out of bowel cancer screening from April 2006, the Department is seeking to raise awareness through working with cancer charities and individual Primary Care Trusts. The Department also plans to roll out pilots with the Healthy Communities Collaborative, designed to raise the profile of cancer and banish any stigma associated with bowel cancer through community-led initiatives.¹⁰

6 C&AG's Report, para 1.13

7 Q 28

8 C&AG's Report, para 1.7, Figure 6

9 C&AG's Report, para 1.2

10 Q 58

2 Support offered to patients during and after treatment

5. Cancer patients reported a high level of satisfaction with important aspects of their care in areas such as trust, respect, dignity and privacy. One fifth, however, did not fully understand or had not discussed with clinicians the potential side effects of treatment. Clinical nurse specialists¹¹ are key to improvements in patient awareness of pain, side effects and complementary therapies, supporting and enhancing the initial overview of treatment provided by the consultant. Work is underway on how best to assess, record and meet patient needs, in particular pain relief, and the need for social support.¹²

6. The potentially debilitating nature of many cancers means that patients often need information about financial benefits available to help with their situation. Three quarters of patients reported that they had not been given information about benefits and of these, half would have liked more advice (**Figure 3**). Work by Macmillan Cancer Relief¹³ has highlighted that not enough people who are entitled to disability-related benefits are aware of them or are helped to claim them. The charity estimated that, over a six month period, benefits worth £106 million to which patients were entitled had not been claimed.¹⁴ Macmillan also established that terminally ill cancer patients with less than six months to live were not always aware that they could claim non-means tested allowances. Primary responsibility for getting benefits to those entitled to them lies with the Department of Work and Pensions, but increasingly cancer information centres are well placed to raise awareness of the financial support available. Acknowledging the need to improve access to benefits, the NHS, the Department for Work and Pensions and Macmillan Cancer Relief are though working together on a training package for healthcare professionals and the Department expected a way forward to be agreed by autumn 2005.¹⁵

11 A clinical nurse specialist is a registered nurse who has acquired additional specialist knowledge and experience.

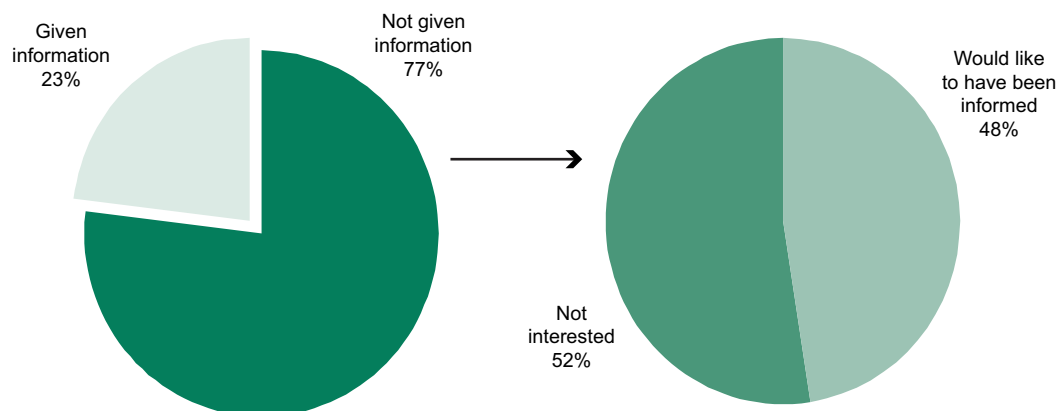
12 Qq 38–39, 41

13 Lee and Allirajah, *The unclaimed millions: DLA and cancer patients*, Welfare Rights Bulletin 181 (2004)

14 C&AG's Report, para 3.13

15 Qq 29–37

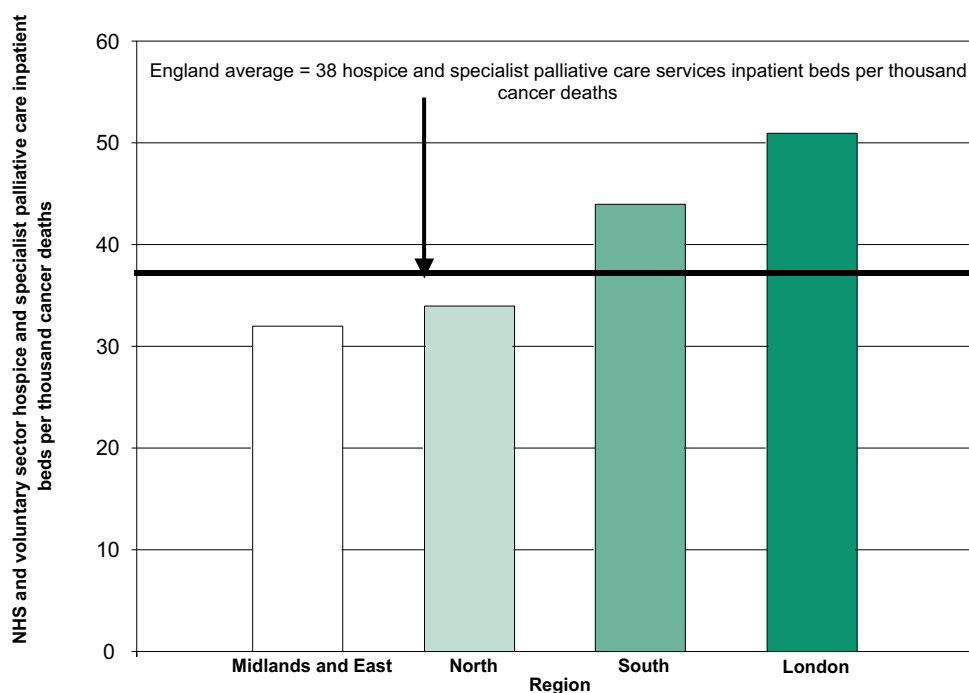
Figure 3: Over three quarters of patients were not given advice on financial and other benefits, although half of those would have welcomed it



Source: National Audit Office

7. Current levels of availability of specialist palliative care vary around the country and do not necessarily reflect areas of greatest need or local population levels. Parts of the North, and Midlands and East regions had fewer hospice and specialist palliative care services per thousand cancer deaths than London and South regions (**Figure 4**). To help redress this regional imbalance, the Department has commissioned the National Council for Hospice and Specialist Care services (now the National Council for Palliative Care) to produce a palliative care needs assessment based on population.¹⁶

Figure 4: Current levels of specialist palliative care vary between regions



Source: C&AG's Report, Figure 63

8. The National Institute for Clinical Excellence has published guidance to help improve supportive and palliative care for adults with cancer, including specialist palliative care. To help implement these guidelines, the Department has allocated additional funding of £50 million a year for three years from 2003–04 to cancer networks to increase hospice care, provide specialist care to cancer patients at home and to train other support services, including district nurses, although the actual amount of additional investment in palliative care in 2003–04 was only £40 million.¹⁷ Some of this money is being used to appoint more consultants and specialist palliative care nursing staff to address shortages of specialist staff and expand these services.¹⁸

9. When asked about end of life choices, people tend to express a preference to die at home.¹⁹ In practice, patients who wish to die at home or in a hospice are more likely to die in a hospital ward, **Figure 5**. A century ago, 90% of people died at home; 50 years ago it was 50%; now it is about 20%.²⁰ Measures have been developed to support terminally ill patients and their families. For example, an increasing number of community teams across the country use the Liverpool Care Pathway for the Dying Patient, which includes symptom control, psychological and spiritual support for the patient, and care of the family and carers after the patient's death. Additional funding of £12 million provided from 2004–

17 *Investment in cancer in 2001–02 to 2003–04*, Department of Health (August 2005)

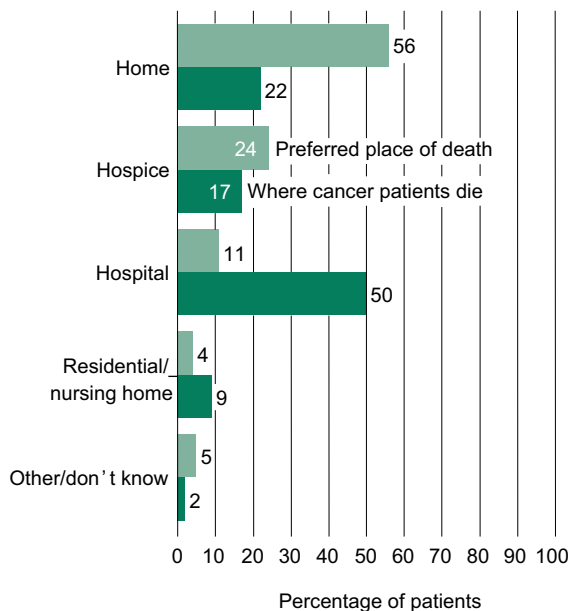
18 Q 9

19 C&AG's Report, para 3.26

20 Qq 11–12

05 for three years has been provided to improve support to terminally ill patients through wider adoption of this and other best practice models.²¹

Figure 5: There is a major disparity between patients' preferred and actual place of death



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).

3 Differences in patients' experiences

10. Prostate cancer patients were less positive about their experiences than other cancer patients, even after allowing for other factors which influence the patient experience.²² In addition, prostate cancer services have not improved as much since 2000 as those for other cancers (Figure 6).

Figure 6: Prostate cancer patients reported less positive experiences than patients with other cancers

	Patients with other cancers 2004 %	Patients with prostate cancer 2004 %	Number of percentage points by which positive responses had increased (declined) since 2000 %	
			Other cancers	Prostate cancer
Waited more than two weeks from referral by GP to be seen by a specialist	37	68	12	4
Had not discussed the side effects of treatment	6	11	9	8
Had not discussed how treatment had gone	5	13	3	1
Would have preferred more information about how treatment had gone	13	20	5	1
Fully understood the explanation of how treatment had gone	81	70	5	3
Have a named nurse in charge of care	61	50	5	7
Did not have home situation taken into account when discharged from hospital	9	13	5	8
Given information about support or self help groups	64	34	(2)	(2)
Had an outpatient appointment cancelled one or more times	11	19	2	(2)

Source: C&AG's Report, Figure 1

11. Although it now kills some 10,000 men each year in England, prostate cancer had been a lower priority for the Health Service than other major cancers for some years. The rise of nearly 50% in detections of prostate cancer between 1996 and 2001 led to huge pressure on services.²³

12. Treatment options are more complex for prostate cancer than for some other cancers. There may be a choice between radical surgery, radiotherapy and sometimes active monitoring.²⁴ In addition, Improving Outcomes Guidance for Urological Cancers, including prostate cancer, was not published until 2002, some six years after the guidance for breast cancer and three years after the guidance for lung cancer. The estimates in the Guidance indicated that increased incidence of prostate cancer would cost between £15 and £44 million per year, while improvements to urological services would cost approximately £13.5 million per year.²⁵

13. The Department is committed to demonstrably large improvements in prostate cancer care over the next four years. Assisted by the Prostate Care Advisory Group, it intends to use the 2005–06 peer review of the compliance of cancer services with national standards to monitor progress and speed up change.²⁶

14. Peer group support networks can be a key source of support, advice and information to cancer patients at all stages in their treatment and aftercare. But not all types of cancer have well developed networked local support groups across the country, and there are fewer support groups available for prostate cancer than for breast cancer. 40% of patients were not given information about relevant cancer support groups (**Figure 7**). The number of patients with breast, bowel and prostate cancer who reported being provided with information on support groups actually decreased between 2000 and 2004.²⁷

23 Q 14

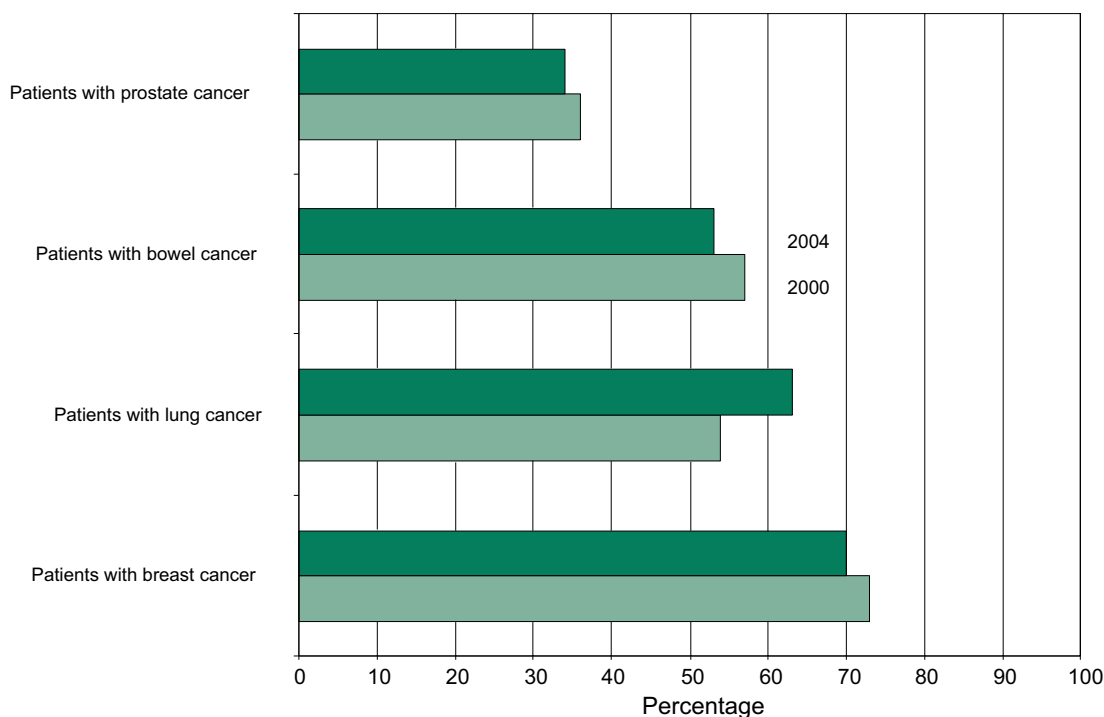
24 Q 16

25 Q 26

26 Q 60

27 Q 17

Figure 7: Patients with breast cancer reported being given information on support or self-help groups more often than those with other major cancers



Source: C &AG's Report, Figure 50

15. Cancer patients in London responded less positively than elsewhere about their experience of services. Yet London had the same or higher levels of expenditure and range of services available as elsewhere in England, and generally clinical outcomes compared well in terms of survival rates.²⁸ The Department attributed the higher than average levels of patient dissatisfaction in London in part to higher staff turnover than elsewhere, affecting continuity of care. High turnover reflected the greater use made of agency staff in London, more inter-hospital transfers of staff, and young staff who trained in London opting to move elsewhere shortly after qualification. To address these issues, the five London Strategic Health Authorities had each asked their cancer networks to produce an action plan to implement the National Institute for Clinical Excellence supportive and palliative care guidance, and the Department would use its 2005–06 peer review to evaluate all services in London.²⁹

28 C&AG's Report, Appendix; Q 42

29 Q 43

Formal minutes

Monday 19 December 2005

Members present:

Mr Edward Leigh, in the Chair

Mr Richard Bacon
Greg Clark
Mr Ian Davidson
Helen Goodman

Mr Sadiq Khan
Sarah McCarthy-Fry
Jon Trickett

Draft Report (Department of Health: Tackling cancer: improving the patient journey), proposed by the Chairman, brought up and read.

Ordered, That the draft Report be read a second time, paragraph by paragraph.

Paragraphs 1 to 15 read and agreed to.

Conclusions and recommendations read and agreed to.

Summary read and agreed to.

Resolved, That the Report be the Nineteenth Report of the Committee to the House.

Ordered, That the Chairman do make the Report to the House.

Ordered, That embargoed copies of the Report be made available, in accordance with the provisions of Standing Order No. 134.

[Adjourned until Wednesday 11 January at 3.30 pm

Witnesses

Monday 21 March 2005

Page

Sir Nigel Crisp KCB, Department of Health, and **Professor Mike Richards**,
National Cancer Director

Ev 1

List of written evidence

Macmillan Cancer Relief

Ev 10

United Brain Tumour Campaign

Ev 12

List of Reports from the Committee of Public Accounts Session 2005–06

First Report	Managing National Lottery Distribution Fund balances	HC 408 (<i>Cm 6712</i>)
Second Report	The regeneration of the Millennium Dome and associated land	HC 409 (<i>Cm 6689</i>)
Third Report	Ministry of Defence: Major Projects Report 2004	HC 410 (<i>Cm 6712</i>)
Fourth Report	Fraud and error in benefit expenditure	HC 411
Fifth Report	Inland Revenue: Tax Credits and deleted tax cases	HC 412 (<i>Cm 6689</i>)
Sixth Report	Department of Trade and Industry: Renewable energy	HC 413 (<i>Cm 6689</i>)
Seventh Report	The use of operating theatres in the Northern Ireland Health and Personal Social Services	HC 414
Eighth Report	Navan Centre	HC 415
Ninth Report	Foot and Mouth Disease: applying the lessons	HC 563
Tenth Report	Jobskills	HC 564
Eleventh Report	Local Management of Schools	HC 565
Twelfth Report	Helping those in financial hardship: the running of the Social Fund	HC 601
Thirteenth Report	The Office of the Deputy Prime Minister: Tackling homelessness	HC 653
Fourteenth Report	Energywatch and Postwatch	HC 654
Fifteenth Report	HM Customs and Excise Standard Report 2003–04	HC 695
Sixteenth Report	Home Office: Reducing vehicle crime	HC 696
Seventeenth Report	Achieving value for money in the delivery of public services	HC 742
First Special Report	The BBC's investment in Freeview: The response of the BBC Governors to the Committee's Third Report of Session 2004–05	HC 750
Eighteenth Report	Department for Education and Skills: Improving school attendance in England	HC 789
Nineteenth Report	Department of Health: Tackling cancer: improving the patient journey	HC 790

The reference number of the Treasury Minute to each Report is printed in brackets after the HC printing number

Oral evidence

Taken before the Committee of Public Accounts

on Monday 21 March 2005

Members present:

Mr Edward Leigh, in the Chair

Mr Brian Jenkins
Jon Trickett

Mr Alan Williams

Sir John Bourn KCB, Comptroller and Auditor General, National Audit Office, further examined.

Ms Paula Diggle, Second Treasury Officer of Accounts, HM Treasury, further examined.

REPORT BY THE COMPTROLLER AND AUDITOR GENERAL

TACKLING CANCER—IMPROVING THE PATIENT JOURNEY (HC 288)

Witnesses: **Sir Nigel Crisp KCB**, Chief Executive, Department of Health and **Professor Mike Richards**, National Cancer Director, St Thomas' Hospital, examined.

Q1 Chairman: Good afternoon, thank you for being so patient. I do apologise, Sir Nigel, that we have had to start this Committee late; it has not happened before and I am very apologetic. Today, we are talking about cancer, the patient's experience, and we are joined by witnesses from Department of Health. Sir Nigel Crisp of course is the Permanent Secretary of the Department of Health and Professor Mike Richards is the National Cancer Director; you are both very welcome. Could I please start, Sir Nigel, by referring you to the Comptroller and Auditor General's Report. Could you please look at figure 5, which you can find on page 10? If you look at the top line of that figure 5, you will see that 42% of patients with cancer were not referred urgently by GPs and if you look at the bottom line, 20% waited more than a month to see a specialist. I know that there are some instances of difficulty of diagnosis, but even allowing for that, is this figure not too high?

Sir Nigel Crisp: Yes it is, but, as you say, about 40% of people who are subsequently found to have cancer did not come through the urgent referral system. The reason for that is that they were not identified right at the outset by the GP as being likely to have cancer. We know that there are some reasons for that which will mean that some patients' GPs simply will not be able to identify, but we think that we can get that number of 40% down to perhaps about 20% by working with GPs. Perhaps as important is that within three years we shall see the maximum waiting times come down to 18 weeks for everybody; we are moving everyone, the urgent and the non-urgent alike, into a much shorter waiting time.

Q2 Chairman: I think with breast cancer your figures are pretty good, are they not? 80% of people with breast cancer are seen within the requisite period. I just wonder why we cannot do that with other cancers.

Professor Richards: I think with breast cancer effectively we are moving towards a position where we see as many people as possible with a breast problem within two weeks. We know that for every person sent to a breast clinic, only about one in 10 or one in 15 actually has cancer, but obviously it is good practice, wherever possible, to ensure that all patients are seen quickly. To a large extent we are managing that in some places with breast cancer, but not in all as yet.

Q3 Chairman: If you now look please at the table which you can find on page 2, you will see half way down that it says a third of cancer patients do not find doctors' explanations of their condition, treatment or tests very easy to understand. Why is that, do you think?

Professor Richards: Again, the first thing to say is that the explanation of cancer, the tests, the treatments is complex and it is complex to explain. That is why we put such emphasis on making sure that clinicians involved in cancer have good communication skills and it is why we back that up with written information wherever possible. I think that one of the things it is important to say is that the proportion who do understand what is going on is going up and I think this report shows that quite well. So there has been an improvement in the four years since the previous survey was done by the Department of Health.

Q4 Chairman: If we look at paragraph 21, we see there in that paragraph a depressing picture about prostate cancer. Why is that?

Sir Nigel Crisp: Perhaps again I may just start off. Of the four cancers that are covered here, we started by giving the highest level of attention to breast cancer, then the other two, and the fourth one that we got to in that order of priority was urological cancers, prostate cancer in particular. This shows simply that we started later on prostate cancer. I think the other thing that it incidentally shows is that the work that

 Department of Health and the National Cancer Director

has actually been done in those other areas works, so we will expect to see prostate catch up with the others.

Q5 Chairman: When? If we were having this hearing in two or three years' time, what would we find out with prostate cancer?

Professor Richards: If we look over the four-year period, we know that the breast cancer guidance was published in 1996, the colorectal cancer guidance in 1997 and the lung cancer in 1999, so they all preceded the first survey done in 2000, but just. They have had the full four-year period between surveys in which to go on showing improvement. The prostate cancer guidance, the urological guidance was published at the end of 2002. I would be confident that in another four years from now, we would see prostate having done a major catch-up. I think we have to make sure that happens as quickly as possible and that is why we have asked each of the cancer networks to produce an action plan on how they are going to implement the guidance and why we also have an appraisal programme where we visit every hospital in the country to make sure that they are implementing the national standards.

Q6 Chairman: When I was talking to the National Audit Office before this meeting, they said that the majority of people who called the cancer helpline about prostate cancer were actually women enquiring about their husbands. Is that right? There are more women calling than men, which would seem to suggest to me that there is a real misunderstanding amongst men of that age group about what they should do about this.

Professor Richards: It is certainly true that men seem to seek advice through helplines less than women, certainly in the cancer field where I know about it. If you look at the internet, that is a different picture, and men do use the internet to find things out, so I do think one has to look at all the different sources of information that there are.

Q7 Chairman: We have talked about prostate cancer and if you look at paragraph 23, we can see again that the London region gives less positive responses. Why is that do you think?

Sir Nigel Crisp: It is difficult to know exactly why. It is not, as far as we can see, about inputs. The same or higher level of expenditure and the same or higher level of range of services are available in London.

Q8 Chairman: Per head?

Sir Nigel Crisp: Per head, yes. Indeed it is not about outcomes either, because survival rates are good. It clearly is something to do with their experience directly of working with staff. There is clearly a people issue. We think a significant amount of that may be about staff turnover and that there is higher staff turnover in London than elsewhere. There may be other issues, including higher expectations and other things to do with London, but we need to find out. The people working in London are trying to understand that in some detail, so that they can make some improvement there.

Q9 Chairman: If we look at hospices now, and this is referred to in paragraph 3.25 on page 39, they have received extra funding of course, but they still say they are under pressure, they are short of specialist staff. Why is this? Is your extra funding inadequate? Is it going to the wrong places?

Professor Richards: We can undoubtedly say that the funding is going to the right places. We have been through a very lengthy and rigorous procedure to make sure that the £50 million that was promised for specialist palliative care is getting to specialist palliative care, that it is getting there based on the action plans that were developed by the local networks and that those action plans were reviewed by panels that had on them people from the Department of Health, the NHS and, most importantly, the voluntary sector as well. We know the money is getting there. The Cancer Plan acknowledged that the voluntary sector was carrying too much of the financial burden for hospice care and that is why we put in the extra £50 million. They are doing a fantastic job and obviously they are also telling us that they are still burdened. In terms of staff, we are increasing the numbers of palliative care consultants. Some of the money, the £50 million, has gone to appointing more consultants and over the next few years we are going to see really quite a major expansion of consultant numbers. In 2002, the number of whole-time equivalents was 169; by 2008 it is predicted that that will be up to 255, which is an increase of over 50%; by 2015 it is predicted that that will reach 383, which is more than double. So we are on track to have more consultants but we need them.

Q10 Chairman: Well, I might ask you more about this on Wednesday, but you will have read in the *Sunday Times* yesterday about a large Report from the King's Fund about your organisation, Sir Nigel. I just wonder whether there is anything here in terms of an accusation that the money has been put in by the Government, but it is not finding its way to the front line in sufficient quantities. Some obviously is.

Professor Richards: I think here that we can categorically say that the money is getting to the front line and for the purposes for which we designed it. We have been tracking that. We have been doing it through the national partnership group on palliative care and that group, which includes representatives from the voluntary sector, has agreed that the money is getting where it is meant to be getting. Yes, they want more, but they are agreeing that the money has got exactly where it was intended to.

Sir Nigel Crisp: May I make one point on that? As I read that article, it was implying that most of the money going into the NHS was going on staff and then it made the imaginative leap to say that was not money being spent on the front line. Well our front line is staff and the fact that we are employing so many more staff and indeed paying them better in a number of areas is really significant. I thought it was rather an odd point coming from the *Sunday Times*.

 Department of Health and the National Cancer Director

Q11 Chairman: Okay, I may come back to that on Wednesday. Lastly, people would prefer to die at home obviously. There is a figure here on page 40, figure 64. Most people do, I am afraid, still die in hospital and would prefer to die at home. So what impact is your initiative on this having at the moment?

Professor Richards: If you look across the course of a century, the number of people dying at home has gone progressively downwards. A century ago, 90% of people died at home; 50 years ago it was about 50% dying at home. Now, overall, taking all conditions together, it is about 20%. A lot of that is due to changes in society as much as to do with changes in healthcare; extended families and things like that. We do know that more people would like to die at home and we are working hard to try and make that possible by making sure the specialist care is available, not only in hospices, but going out into people's homes through the community teams that are run across the country and also by skilling up generalists, that is GPs, district nurses and others. We have been doing a lot of work to skill up, first of all district nurses, that was something that we started back in about 2001, and more recently our end-of-life care initiative, which is aimed at GPs and care homes as well, another important area for investment in teaching people about how to care for the dying.

Q12 Chairman: Is it a question of who pushes hardest, if somebody insists? Is it down to the patient?

Professor Richards: Certainly one of the key things is to elicit from a patient what their preference is about where they wish to be cared for. One of the things we have to do is train staff to elicit that from patients. That is quite a sensitive thing to be asking patients about, but it can be done and there is a very good programme going on up in the North West of the country looking at preferred place of care and how you can both elicit that from the patient and then document it, so that everybody knows. There is also good evidence that where you do elicit that information, people are then more likely to have their wish fulfilled.

Q13 Jon Trickett: As I mentioned last time we looked at this subject, my own mother died of cancer last year and so for about two years, I was in and out of cancer wards and also up to the radiotherapy hospital. My mother came home and finally died in a hospice. I did therefore see the full range of care for her and I was incredibly impressed by the skill and patience and sometimes the miraculous work which was done by your staff. I should like to say that by way of preface, because it would be easy to give the impression that a lot of the experience is negative, which it is not, not in my own personal experience anyway. On prostate cancer, I do not think we are doing very well frankly. I noticed, for example, that 68% of prostate cancer patients wait more than a fortnight for referral to see a specialist, compared with 37% for other cancers. Why is that? May I just

say that I understand prostate cancer is now the biggest killer of men? It has just overtaken cardiovascular problems.

Professor Richards: No, it is not the biggest killer. I think lung cancer is still the biggest killer, but I think it is the second largest.

Q14 Jon Trickett: How many men a year die from prostate cancer?

Professor Richards: From prostate cancer, about 10,000 in England. So it is a major killer. Part of the reason is that there is huge pressure on services because the number of cases being detected has gone up enormously over a five-year period, probably getting on for nearly 50% between 1996 and 2001 and that is because of the much wider use of the PSA test, the Prostate Specific Antigen Test. As you will know, there is a lot of controversy about the value of that test, but one thing which is absolutely clear is that if you have the test, and people are going for the test more, you do pick up more cases. Some of those cases might never have caused trouble during a patient's lifetime but that is putting pressure on the services, on urologists, on the radiotherapy services, a whole range of different services. One of the things that we are doing there is to develop new roles, particularly for nurse practitioners, in assessing patients with lower urinary tract symptoms which could be prostate cancer, but could just be benign prostate disease. That is something that over the next few years we need to do more of in terms of having those nurse practitioners in place to do those assessments.

Q15 Jon Trickett: Yes, but even so, on the question of nurses, in 50% of prostate cancer patients, there is no named nurse in charge of the care, which seems to rebut the case you have just made, compared with less than 40% for patients with other cancers. That is not really a satisfactory explanation, is it?

Professor Richards: It does not rebut the case I have just made. There are two separate issues here: one is about clinical nurse specialists who provide information, support and continuity of care for patients once they are diagnosed. That is enormously valuable, you are right, we do not have enough of those yet, we are in the process of appointing more at the moment. Separate from that is the nurse practitioner, who performs the initial assessment of patients who may very well have benign disease. We need both of those groups of clinicians to tackle prostate cancer.

Q16 Jon Trickett: Why are we not explaining to men with prostate problems the situation that they are in and why are we not referring them to self-help and support groups? Why are we not discussing in sufficient numbers the side effects of the treatment? I think special counselling is required with prostate problems, is it not, because frequently they develop so slowly that a balanced judgment has to be made about whether to operate or not? Obviously the operation itself can have quite severe side effects, can it not? Why are we letting them down in terms of counselling?

 Department of Health and the National Cancer Director

Professor Richards: You are absolutely right. The explanation of the different treatment options is actually more complex for prostate cancer than it is for some other cancers. For prostate cancer, there may be a choice between radical surgery, radiotherapy and sometimes active monitoring, which means carefully watching the patient, doing the PSA measurements, but not necessarily treating them initially. Again, what we have found is that the nurse specialists are very good at offering advice and helping people to come to the right decision on that, which is the reason why we are so keen to see more nurse specialists in this area. It is also why we are making sure that the doctors are trained in communication skills so that they can explain these things better too.

Q17 Jon Trickett: Two thirds of all patients with prostate cancer get no information at all about support or self-help groups as opposed to one third of patients with other cancers. You know, do you not, because I spoke to you, that I encountered two men in one morning in my constituency? I do not know whether you recall the conversation; I certainly do. I went out one morning in part of my patch and encountered one man who had been waiting six months for treatment and nobody was giving him any advice at all. He just stopped me in the street. Bizarrely, later in the morning a second man came to me and both had been diagnosed in May or June and we were then in November waiting for treatment. What on earth is going on? Why is advice not being given?

Professor Richards: I think what is happening with prostate cancer is, as this Report shows, that it is lagging behind the other cancers, but we have now put in place the guidance and we are implementing that guidance and that is why I am personally confident that we will see major improvements in prostate cancer over the next few years. On the specific point about support groups, I think there are fewer support groups available across the country for prostate cancer than there are, for example, for breast cancer. Part of the reason that they may not be being talked about is that they may not exist. These are services which are in evolution and one of the important things that we have done for prostate cancer is to set up a prostate cancer advisory group at the Department of Health. This brings together key charities like the prostate cancer charity with the Department of Health and with NHS clinicians who are dealing with prostate cancer on a daily basis. They are advising me on any further measures that we need to take on prostate cancer.

Q18 Jon Trickett: I am not trying to give you too much of a hard time, but I am told by a senior clinician in my patch who deals with prostates that there are dozens, possibly over 100 men, who have been waiting more than six months for treatment, having had a pre-operative assessment. Does that figure sound plausible?

Professor Richards: I would need to be aware much more about what treatment and for which patients. That does not sound right because what we know in

practice is that the vast majority of people are being treated within one month of the decision being made that they need treatment.

Q19 Jon Trickett: On prostates?

Professor Richards: On prostates.

Q20 Jon Trickett: Given the nature of prostate cancer, it may be that the clinical decision has been taken not to do a surgical intervention, but the fact is that the patients do not seem to be aware that that decision has been taken. I cannot think of anything more isolating for a human being than to be left at home knowing that they have prostate cancer—and I have told you this myself on the telephone—that the cancer has not yet breached across into other organs and not to know what is happening and to be ringing in weekly asking “When am I going to be told something?”. There cannot be anything worse than that.

Professor Richards: Again, if you want to put me in touch with the person—

Q21 Jon Trickett: I did. I gave you the names by e-mail.

Professor Richards: You certainly have not told me about the number of people waiting.

Q22 Jon Trickett: Finally then on prostates, how much additional resources do you think are required, or are you putting additional resources in to try to tackle the backlog which appears to be larger in this particular area than in other cancers?

Professor Richards: We are putting a lot of extra resources in to areas that are directly relevant to prostate cancer. Clearly one of the areas that we are investing in is radiotherapy, which is one of the treatments for prostate cancer. There, we have doubled the number of radiographers in training in order that they can operate the radiotherapy machines and we have put in more new radiotherapy machines than ever before. We still do not have enough and I am in no way complacent about that, but we have put in place the steps so that people can get radiotherapy without delays. On the surgery side, the delays are not usually so much of a problem, but, again, we are monitoring that very closely to make sure that is the case.

Q23 Jon Trickett: Are there patients with cancer who are unable to receive timescales for radiotherapy treatment because of the lack of radiotherapists?

Professor Richards: That should not be the case. They should always be given a time when they will be having their radiotherapy. As I have said, there are unacceptable waits for radiotherapy, I have made no secret of that, and we are tackling them as hard as we can go.

Q24 Jon Trickett: Would it surprise you to know that I told your office of the case of a woman who had had a mastectomy and who received a letter saying that there were no radiotherapists and no prospect of her having any radiotherapy?

 Department of Health and the National Cancer Director

Professor Richards: I am not aware of you having let me know about that particular patient, because if you had, I would certainly have looked into it.

Q25 Jon Trickett: Do you think she is the only person in the country or do you think there are others in her situation?

Professor Richards: I have said already that I believe that there are unacceptable waits for radiotherapy. I have also said that we are tackling those as hard and as fast as we can. I think we have a very reasonable programme in place. This is because historically we have not been training enough therapy radiographers and that is why we have doubled the number in training. That is the main obstacle that leads to radiotherapy waits.

Q26 Jon Trickett: Could you just give us a note on the additional amounts of money dedicated to prostate cancer which you want to see going in and perhaps some targets in terms of benchmarking progress, so we can measure progress over the years to come? All I have said does not detract from the first point I made, which was that I think you have some absolutely wonderful staff in the NHS dealing with cancers. I would not want to leave any other impression than that.

Professor Richards: I absolutely agree with that and thank you for that. I would also say that when the National Institute for Clinical Excellence produced its guidance on urological cancers, within that guidance there were estimates for the amount of extra funding that was required for urological cancers, and we can provide that to you.¹

Q27 Mr Jenkins: I should like to echo Mr Trickett's comments with regard to the staff and pass our thanks on to your staff in the service for the work they do for people.

Sir Nigel Crisp: We shall make sure we do that.

Q28 Mr Jenkins: I was rather surprised, listening to Mr Trickett, because a friend of mine, only a week or so ago, told me about a mutual acquaintance who had been to see his doctor and from the time he saw his doctor to the time he came back home after having an operation to remove his bowel cancer it was four weeks. I was surprised at that. I thought four weeks was a very fast time. I thought it might be about five or six weeks, but I thought four weeks from the time he saw his doctor to coming back home was marvellous. It really was a standard to which we should aspire for all patients across the country, though I know about the difficulties with regard to staffing in different areas, different trusts *etcetera*. The one thing which does concern me, and I know it concerns a lot of people, is that when you have people going into hospital to see a consultant and they are in a state of anxiety, sometimes when they are talking to the consultant, they do not hear every word the consultant utters. They hear the good sentences, the good news but they tend to shut out

the bad news. I was surprised to see that only 10% of the patients receive a written report on the consultation. That is a contract in effect between the consultant and the patient and NICE laid down a stipulation with regard to it being 100%. How do we get to 100% for this arrangement?

Sir Nigel Crisp: I will make a couple of points and then bring in Professor Richards again. We have on page two the statement that two thirds of patients found the doctor's explanation of the condition adequate. I would also note the very big figures at the bottom where the confidence and trust in the doctor at the last outpatient appointment has leapt from 68% to 84%; so we are moving in the right direction. You refer to a specific point that is made in here, which is that the NICE guidance said that we should give something in writing to the patient. It actually came out in March 2004, round about the same time as the research for this document was actually being done. So we expect that to be improving, because I absolutely take the point, that actually we want some kind of record although the record could be of different sorts. It could be a letter from the doctor, it could be a recording of the interview, it could be a whole range of different things. Perhaps Professor Richard could pick that up?

Professor Richards: When I was in clinical practice myself, one of the things that I used to offer to do for patients with breast cancer who came to see me, often for quite difficult consultations about chemotherapy, was to audio tape that consultation so that they could take it home. We followed that up with a survey and found that patients liked that, they did listen to information afterwards and, exactly as you were saying, a comment that came back time and time again was "I hadn't heard you say it, but it was on the tape" which I think proves what you are saying. That is one way you can do it. You can also do it by writing a letter directly to the patient, possibly copying that letter to the GP. That has been done in Australia and there has been a randomised control trial showing it is beneficial, so that was also recommended in the NICE guidance as an option. What the NICE guidance did not do was say, it must be one or other of these, it just said that from now onwards we should be taking this step of giving patients a report of some description of that consultation. That should apply to any key consultation, anywhere in the care pathway. It may be when they get the diagnosis, or it might be later when they have a relapse of cancer, for example.

Q29 Mr Jenkins: I want to slip into a different strain of questions now. You know that cancer patients particularly are entitled to certain benefits. I do not expect the consultant to sit down and discuss the benefit system with the patient, but whilst people have the fear of being treated and going through this issue, the uncertainty of benefits and finances can play very heavily on their mind. Do we have some situation in place where we are now starting to target, either the Department for Work and Pensions (DWP) or we are finding some way of

¹ National Institute for Clinical Excellence (2002), *Guidance on Cancer Services: Improving Outcomes in Urological Cancers: The Manual*.

 Department of Health and the National Cancer Director

linking these people up at an early stage to ensure that they actually draw the benefits they are entitled to?

Sir Nigel Crisp: I think the answer is that it is not good enough. I think that was one of the things which came out of this Report on page 35, where it actually draws out the fact that not enough people who were entitled to benefit actually knew about it or were helped to find it. We do not have strong enough systems in place to do it.

Q30 Mr Jenkins: That is the problem. Now I want a solution.

Sir Nigel Crisp: The links to that and another theme that you have seen in this Report are cancer information centres and the growth of cancer information being provided actually within hospitals and within services which will enable us to do that. May I ask Professor Richards to pick it up?

Professor Richards: I too recognise it is as a problem. I also welcome the spotlight that has been put on this by Macmillan Cancer Relief,² because they have been particularly highlighting this. We are working with them and with the Department for Work and Pensions. What we need is a package of training for healthcare professionals, for nurses and doctors, not to make them experts but to give them adequate knowledge of the benefit system, that they can be the primary source of advice to patients, then the patients can be passed on to real experts in the benefits thereafter. I do think that healthcare professionals need to have that training, so that they can help the patients at the front line.

Q31 Mr Jenkins: Do you feel that is the best route? I should have thought the aftercare professionals had enough to do, to be honest, and although they may have an understanding and they can advise people where to go, it should be the Department for Work and Pensions which should be picking it up. Are there any consultations and discussions with the Department?

Professor Richards: Sure, we are in consultation with the Department for Work and Pensions on this and we have a tri-partite group: the Department of Health, Work and Pensions and Macmillan Cancer Relief. I think the role of the healthcare professional here is one of sign-posting. I am not asking them to be experts, but they do need to know enough about who might be eligible for things to point the right people in the right direction. If we did that, then we would be able to make use of all the staff available to DWP.

Q32 Mr Jenkins: I know you have this tri-partite group. Who is the lead in this tri-partite group? I still think it is the Department for Work and Pensions which should be leading this. It is their responsibility to get these benefits to these people who are entitled to them, is it not?

Professor Richards: We are working very closely and as equal partners in this, because we are very concerned to make sure that cancer patients benefit from this, as they are; we are working as equal partners in this.

Q33 Mr Jenkins: And this is the model you prefer. You are going to work as a tri-partite group with no-one taking the lead.

Professor Richards: I think it requires all of us to make this happen. I do not think it is a question of one party being in the lead or not. I think we need to get our own house in order, which is about making sure that our staff knows enough about this. This is something that matters to patients and our staff should know about it so they can point patients in the right direction. That is all I am asking.

Q34 Mr Jenkins: Is this rolled out to a point where you are going to make an announcement? Are you going to send this down to the—

Professor Richards: No, not as yet, but we are working with Macmillan.

Q35 Mr Jenkins: When do you expect it to be finalised?

Professor Richards: I do not have an exact timescale in mind.

Q36 Mr Jenkins: I did not expect “a week Thursday at 2 o'clock”. I expected 2005, 2006, whatever you think.

Professor Richards: I think that during the course of 2005 we ought to be able to get our position clear on what needs to be done.

Q37 Mr Jenkins: So before Christmas. About September, October, November 2005 we should start to see the paperwork roll out as to the way forward.

Professor Richards: Yes, we ought to have agreed a way forward on it by the autumn of this year.

Q38 Mr Jenkins: It is very much about information; I appreciate it is a very difficult area to get information to patients and elicit the answers you want from these patients. It is the same with regard to side effects; a quarter of patients do not fully understand the side effects of the treatment they are going to undergo. I do not believe anyone could understand what pain is like until they have actually suffered the pain. You cannot describe it; trying to describe pain is difficult. It is the side effects, the pain issue; we still seem to have a break in the link somewhere of getting this information back to the consultants, back to the aftercare professionals, to the patients. Do you feel there is more to be done in that area?

Professor Richards: There is undoubtedly more to be done, but it is one of the areas where we have seen a marked improvement. Four years ago only 63% of patients were saying that they had a complete understanding of their side effects; that has now risen to 76%. There is still a long way to go, but it is a fairly marked increase over only a four-year period.

² Ev 10.

 Department of Health and the National Cancer Director

Q39 Mr Jenkins: It is a quarter. Where is the breakdown, where does the link break down? I should have thought that, as a part of the explanation to start off with, they would be told what side effects to expect.

Professor Richards: Absolutely, and this is one of the areas where very often it is the consultant who will give an overview of the side effects and then that will be supported and enhanced by the information that the clinical nurse specialist gives. That is an extremely valuable role and it is because we have more of those nurse specialists that we have seen this improvement that there has been over the last four years.

Q40 Mr Jenkins: But there should in effect be a package for the patient and boxes which should be ticked to show that they have now received the benefits advice, they have now received the side effects and they have now received the pain identification and what to do about it and where to come back to.

Professor Richards: Yes.

Q41 Mr Jenkins: Obviously those tick boxes are not being ticked at the present time.

Professor Richards: One of the things that we are doing more work on at the moment is how best to assess patients' needs across the whole range of things, from pain relief, through financial benefits to social support, whatever it may be, so that we can make sure that the patient's needs are, first of all, discovered and then we can act on it. If we do not ask patients about their financial status, we are not going to know who should then be referred on to DWP.

Q42 Mr Williams: Why is it that the London experience seems to be so bad? Looked at as a Welsh MP, we think of London as having the great training hospitals, much easier to recruit consultants and medical staff. So what has gone wrong? Why is it that London at the end of all that seems to have a worse experience than their neighbouring regions?

Sir Nigel Crisp: As I said at the beginning, I agree with you, the inputs are actually, if anything, better in London. The inputs, the amount of money, the resource going in is, if anything, the same level or maybe better in London and the outcomes, in other words people's survival rates are, if anything, better in London again. It is actually something about just how they are treated and some kind of people factor. We think the biggest issue on this is staff turnover and therefore not continuity of care, continuity of the conversation, continuity of the point about information which Mr Jenkins has been pulling out. We are actually trying to understand it in much more detail for the all communities in London, because, again, London is not remotely homogenous in terms of what people need. That is why, this having come out so clearly here and elsewhere, a lot of work is now going on in London to try to identify what it is that would make a difference.

Q43 Mr Williams: In a way we are surprised that you were surprised. We would have expected you to have identified this a lot earlier, particularly practising clinicians.

Professor Richards: I do not think there is any one single reason for it. I agree with Sir Nigel that it is likely to be staff turnover. I think it is worth remembering that a lot of young people come to train in London, they may spend a year or two working in London. Then they may choose to move elsewhere in the country, whereas in some other towns and cities, people are there for life, if you like, so it is a lot easier to provide continuity of care. What we have to do is to make sure we have the systems in place to overcome that, even though there may be a higher natural turnover in London. We know, for example, that more agency staff are used in London. There is more transfer of people from one hospital to another in London because they can move from hospital A to hospital B and they do from time to time. Each of the five Strategic Health Authorities in London is taking this very seriously. I alerted them to these findings. They have written back to me. I have talked to several about it. North East London Strategic Health Authority is taking a lead on this on behalf of London. They have some extremely interesting work going on in Newham in terms of black and minority ethnic groups to see what their experience of care is. Equally, the King's Fund have taken a major interest in this. They produced a document called Capital Health a couple of years ago and they are interested in working with us. What we are doing in practice is that each one of the five strategic health authorities has asked its network to produce an action plan to show how they will be implementing the supportive and palliative care guidance from NICE. We will be then making sure that those action plans are implemented. We will also be reviewing all the services in London through our peer review assessment programme and that is being done during the course of this year. We will ask the teams which are going round doing that to pay particular attention to the patient experience and what is being done locally.

Q44 Mr Williams: We have the inter-regional information here, the comparative response in relation to London. You have referred to an intra-regional league, the regions within the region. Do we have the same degree of variation within the regions within the London region?

Professor Richards: It is important to remember that for this survey only a sample of trusts were chosen. I think half a dozen trusts in London took part in this survey and about 43 or 44 from outside London, so we do not have the full picture for London. In the previous survey, back in 2000, every trust in the country took part in that, but on this occasion, it was just a sample. I think what we can say is that collectively the experience of care for Londoners was less good than elsewhere, but what we cannot say is, within London, whether one place was particularly better than another.

 Department of Health and the National Cancer Director

Q45 Mr Williams: And yet there will be some centres of excellence in amongst them.

Professor Richards: Yes, but even with that each one needs to look at its own results and make sure they are as good as we would hope them to be.

Q46 Mr Williams: If someone came to you and said they had a choice of treatment in London or treatment in, say, the Manchester area, would what you have just said lead you to say “Steer clear of London”?

Professor Richards: No, because as Sir Nigel Crisp said just a minute ago, the results in terms of survival rates are every bit as good in London as they are elsewhere. I think we need to look at the whole picture. The patient’s experience is one part of it. We need to look at the survival, we need to look at the use of anti-cancer drugs, the waits for radiotherapy, everything and put it together. When I have done that, there is no one part of the country that I would say is perfect on everything and no one part that is worst on everything. They all have things that they need to improve on.

Sir Nigel Crisp: May I just make one point on that which is that these were six hospitals in London—I think it was six—and they ranged from those that you would know terribly well to less well known ones.

Q47 Mr Williams: You were not necessarily comparing like with like in each of the sub-regions?

Sir Nigel Crisp: That is probably true, but I actually think the challenge to those hospitals is: why do patients prefer the experience in Manchester? I think they need to look very clearly at what it is that they are doing in Manchester that may be a better experience, even if the outcome in London may be better and the inputs in London.

Q48 Mr Williams: Is that being studied?

Sir Nigel Crisp: The cancer networks do sit down and learn together and patient experience has now recently become much higher as one of the things which are being looked at through the cancer collaborative.

Q49 Mr Williams: That sounds fine. I have no doubt it is what happens when specialists meet together in conferences and that sort of thing, but how systematic is this process of learning the good practice from other areas?

Professor Richards: It is systematic. I get all 34 of the cancer networks in England together three times a year, that is the medical director of the network, the network manager, the lead nurse and a whole range of other people involved in those cancer networks, about 300 or more people. We get together three times a year at a conference in order that we can make sure that we are sharing experience across all the networks, that I can communicate things out from the Department of Health and, most importantly, so that I can hear from them what their problems are.

Q50 Mr Williams: That is fine. That is exchange of personal opinion, but it is therefore highly occasional. Are you systematising this, are you now following up this realisation with statistical analysis for our next report?

Professor Richards: Yes.

Q51 Mr Williams: I am not trying to catch you out.

Professor Richards: We are. We measure a whole lot of different things on cancer. We have already talked today about waiting times for cancer and those are collected in every hospital across the country in order that we can see the different positions. We also have this peer review programme where we visit every hospital, but where the hospitals are assessed against a very detailed manual of service measures. It is a thick document and that will give us a very clear readout on whether hospitals have the necessary services in place, for example whether they have the clinical nurse specialists that I have been talking about. So that is being done and we are in the middle of a round of the peer review visits at present.

Q52 Mr Williams: Coming back to a point which has been raised by my colleague, the written reports. A lot of people obviously are in a virtual state of shock when they are receiving their diagnosis and when they are talking things through. They may not comprehend and indeed, in so far as there may be technical language, it is may be that they do not understand what is being said. How automatic is the written report becoming, and is this not particularly important, thinking of a section of the report which refers to a fortunately relatively low percentage of cases, but still too many cases, where the consultation about diagnosis lasts only ten minutes. If it is a very short time and the person is being given bad news and is in shock, it is doubly important, is it not, that they have something they can take away to discuss with their families?

Professor Richards: I agree that it is good practice and I was delighted that the NICE guidance specifically recommended it. Remember that that guidance only came out in March of last year and so did not affect the patients in this survey who were being surveyed at exactly that time. We will have to reinforce these messages, that this is good practice, we will have to encourage teams across the country to adopt this practice, but that I am absolutely committed to do, because having delivered that sort of practice myself, I know it is both feasible and I know it is highly acceptable to patients. I personally will encourage it as much as I can.

Q53 Mr Williams: How difficult does it become for you, and I recognise that this is patchy around the country, with linguistic difficulties now becoming a factor? Is this complicating the application of this process?

Professor Richards: That is an additional complicating factor. I think we still really have quite a long way to go with people who do read and write and understand the English language. In terms of foreign languages, one of the programmes which has in fact been funded through the lottery is a telephone

 Department of Health and the National Cancer Director

helpline to CancerBACUP, the information charity, where there are interpreters available for the 12 commonest foreign languages. That does at least mean that there is a direct access, they can phone the nurse who is on the helpline and it is a three-way conversation then, with immediate access to an interpreter. Equally, at a local level, hospitals have their own arrangements for interpreters and clearly they know what foreign languages are most likely to be spoken on their patch.

Q54 Mr Williams: But it makes it more important that they have this piece of paper if they are going to have to get advice over a phone, does it not? There is something to work on.

Professor Richards: Absolutely, but this is a new and very welcome recommendation that we will now implement into practice.

Q55 Mr Williams: May I ask one final question, Chairman? I was surprised to see that as high a proportion as a quarter of patients have not been warned of side effects. It is a bit like fear of flying: things that are unpleasant can often be tolerated better when you understand why they are happening. Why is it that as many as 25% are not warned of what side effects to expect? This is in figure 17.

Professor Richards: I think the exact wording was something to the effect that the percentage of those having a complete understanding of the side effects was 76%. There is a further proportion that had some level of understanding; in fact I think it is figure 17 on page 18. There is a group there, just over a further 10%, saying "Yes, and I understood some of what was said". However, there are those, just one up from the bottom, who say "No, side effects were not discussed at all". Now that, to my mind, is unacceptable but I think you will agree that the proportion for whom that was true has decreased very considerably between 2000 and 2004, by more than half, just looking at that graph.

Q56 Mr Jenkins: We see on page 28 that the Princess Royal Hospital at Hull has an integrated support system which seems to be first class and admirable. Why is it so there and what plans do you have for rolling this system out?

Professor Richards: A number of hospitals do now have different forms of information and support centres and this is just one very good example in Hull. It is an excellent example, but there is an excellent one at Mount Vernon Cancer Centre, one at my own hospital at St Thomas's, a variety of ones around the country supported by Macmillan Cancer Relief. We do have a number of models of information and support centres which give people direct access to any information they want about cancer, but also where they can come and often where there are complementary therapies offered, counsellors available. Those services which did not exist five to 10 years ago, or were very rare, are now becoming much more commonplace and the one in Hull is one of them.

Q57 Mr Jenkins: So when do we expect to see this sort of service at every centre for the treatment of cancer?

Professor Richards: Again, the NICE guidance sets out what services should be available to patients in this way and we will be monitoring the implementation of that guidance through the peer review appraisal programme that I described a minute ago.

Q58 Mr Jenkins: What are you going to do, Sir Nigel, to raise awareness amongst men of colon and bowel cancer?

Sir Nigel Crisp: I am going to refer again for some of the detail to Professor Richards, but a large number of campaigns is starting to take place. We put quite a lot of money into it. The other day I noticed one that we are doing specifically aimed at groups from Asian backgrounds. We are actually getting much more segmented in terms of our specific targeting of particular people whom we think we need to get information to. That is the broad approach that we have been taking, but I do not know specifically on bowel cancer.

Professor Richards: This is a very important topic for us at the moment, particularly as we are going to be rolling out the bowel cancer screening programme from next April. It is extremely important that men and women in the population are aware of what bowel cancer is and also the value of screening which undoubtedly saves lives. Several trials have shown this now. I think we all agree on that. We have to get those messages through in every possible way we can. We are working with the relevant charities; for example, for bowel cancer with Beating Bowel Cancer as a charity to raise the profile and I attended a meeting with them just a week ago to do this very thing. We are also planning to work with individual primary care trusts and a programme called the Healthy Communities Collaborative. They have been extremely successful in working with communities, particularly with elderly people in the communities, to reduce the rate of people who have serious falls in the community. If they can do that for people falling over, we believe they can also do it to raise the profile of cancer and we are working with them to roll out some pilots as soon as possible.

Q59 Chairman: Just one last question, by way of summary of this afternoon's hearing. Obviously a lot of the work we do in this Committee is terribly important in terms of saving money, but this impacts directly on people and therefore is a very important hearing. When you appear in front of us in four years' time, what improvements to these figures do you think we will see?

Professor Richards: I think we will see the continuation of the upward trend that we have seen over the last four years.

Q60 Chairman: That is pretty vague.

Professor Richards: I had not finished. We have seen improvements in a whole lot of areas in this report and I think we will see the same amount of

Department of Health and the National Cancer Director

improvement again. Specifically, I think we will see improvements in prostate cancer, because we now have the guidance in place. That, combined with the support and palliative care guidance, will see a major improvement and I would be confident that in four years' time, we will be able to demonstrate that to you.

Q61 Chairman: But it would not be up to the level, say, of breast cancer. You could not offer that, could you?

Professor Richards: I hope breast cancer itself will go on improving. I hope that we will have narrowed the gap and I hope that prostate cancer will be where breast cancer is and chasing hard.

Q62 Chairman: We will hold you to that. Thank very much.

Professor Richards: That is fine. I am happy.

Chairman: Thank you Professor, thank you Sir Nigel. I am very sorry for the late start. Thank you.

Memorandum submitted by Macmillan Cancer Relief

The National Audit's office recent Report, Tackling Cancer: Improving the Patient Journey highlighted that although there has been record investment in cancer over the last few years there is still a long way to go.

We were particularly concerned at the lack of financial support and benefits advice given to patients. The NAO Report found that three quarters of patients were not told about benefits. Half of these people said that they would have welcomed this information if offered.

Our own research for our "Better Deal" campaign confirms the paucity of information and the severe impact financial hardship has on many people affected by cancer. Just as patients are not expected to manage their pain without help we believe that support to navigate the benefits system must be an integrated part of the care package. Moreover, ensuring that every cancer patient has access to specialist benefits advice at diagnosis is in line with the NICE Supportive and Palliative Care Guidance (2004) which clearly identifies the need for assistance for cancer patients tackling the benefits system.

Macmillan would be interested to know:

- (i) What discussions the Government have had with the Department of Work and Pensions regarding benefits advice for cancer patients,
- (ii) Who else they have been consulting with on the issue,
- (iii) What model of advice provision they favour,
- (iv) When they might make an announcement about plans to tackle the issue to ensure that these shocking statistics have improved significantly in a future National Audit Office report into cancer standards.

I have enclosed a copy of our parliamentary briefing note on our "Better Deal" campaign which further highlights why we feel the current benefits system is repeatedly letting down people with cancer.

Fiona Ferguson
Parliamentary Affairs Officer

16 March 2005

PARLIAMENTARY BRIEFING: STOP CANCER SPREADING TO PEOPLE'S FINANCES

Cancer patients tell us that they suffer financial hardship as a result of having cancer, more than three quarters of people we surveyed said that they ran up extra bills.

For most people affected by cancer, money worries are second only to pain as a cause of stress.

The Disability Living Allowance (DLA) and Attendance Allowance (AA), which should ease the burden for many patients, are designed for long-term conditions.

Cancer is different. The benefits system fails to reflect this. It must be changed urgently.

The debilitating effects of treatment are frequently immediate and drastic. Equally drastic can be the sudden extra costs such as travel for treatment, hospital car parking and heating. This generates urgent need for benefit support.

The pattern of needs is also very different. The care requirements of a cancer patient will vary hugely depending on the nature and course of their treatment. Their needs at each stage are not predictable and can be acute, as people react very differently to treatment and accurate prognosis of the disease is difficult.

This is why Macmillan Cancer Relief is launching a new campaign to highlight what needs to be done.

MACMILLAN IS CALLING ON GOVERNMENT TO:

1. Ensure every cancer patient is offered specialist benefits advice at diagnosis.
 2. Change the law to improve cancer patients' access to OLA and AA by:
 - Waiving the three to six month qualifying period for cancer patients claiming OLA and AA.
 - Allowing hospital in-patients to keep their OLA or AR for 52 weeks.
 - Scrapping the 28 day linking rule.
 - Changing the definition of terminal illness from six to 12 months.
- Action on these calls will help transform the lives of people confronting the reality of dealing with cancer. They deserve a better deal.

THE SOLUTION

1. Ensure every cancer patient is offered specialist benefits advice at diagnosis.
 - Our research shows that 54% of people who die as a result of cancer have not received DLA or AA.
 - Our evidence indicates that an important reason for cancer patients failing to claim benefits is that they simply did not know about their entitlement.
 - People must be advised about DLA and AA because it often can bring entitlement to linked benefits such as Carer's Allowance or extra Income Support.
 - Getting this right is key to Government realising its aim of more joined-up health and social care.
 - It would also be consistent with the NICE Supportive and Palliative Care Guidance (2004) which identifies the need for assistance for cancer patients tackling the benefits system.
2. Change the law to improve cancer patients' access to DLA and AA by:
 - Waiving the 3–6 month qualifying period for cancer patients needing DLA and AA

CANCER PATIENTS CANNOT AFFORD TO WAIT THREE OR SIX MONTHS BEFORE GETTING DIA OR AA. BUT THE DLA/AA SYSTEM, GEARED TO PEOPLE WITH CHRONIC CONDITIONS, DOES NOT TAKE ACCOUNT OF THE OFTEN URGENT CARE NEEDS GENERATED BY THE IMMEDIATE, DEBILITATING EFFECTS OF CANCER TREATMENT.

Cancer patients are also already incurring extra costs such as travel to and from hospital, special diets, new clothes, increased heating bills and prescription charges.

The three to six months qualifying period for DLA and AA is waived for terminally ill patients. The same rule should apply to other cancer patients who may not have a terminal diagnosis but who have substantial care needs.

Allowing hospital in-patients to keep their DLA or AA for 52 weeks and scrapping the 28-day linking rule.

IN-PATIENTS LOSE THEIR DLA AFTER FOUR WEEKS, AND SHORT STAYS IN HOSPITAL CAN BE LINKED TOGETHER AND IF THEY AMOUNT TO 28 DAYS BENEFIT IS WITHDRAWN. BOTH MEAN THAT CANCER PATIENTS MAY LOSE SOME OLA AS A RESULT OF TREATMENT. THIS IS UNFAIR.

People in hospital still have bills to pay.

Extra costs include telephone calls home, family members taking time off work to visit and their travel costs.

Patients should not have to arrange treatment to fit around the benefit system—and yet we know this happens.

Extending the entitlement to 52 weeks would align DLA with other benefits.

Changing the definition of terminal illness from six to 12 months.

CURRENTLY ONLY PEOPLE NOT EXPECTED TO LIVE LONGER THAN SIX MONTHS QUALIFY FOR DLA AND AA UNDER THE TERMINAL ILLNESS "SPECIAL RULES" TO FAST-TRACK SUCH CANCER PATIENTS THROUGH THE SYSTEM.

Our research has shown that take-up is poor and the rules need to be reviewed to take account of improvements in treatment and palliative care, which make it more difficult for doctors to make such precise judgements about life expectancy for cancer patients. Our joint report with the Northern Ireland Social Security Agency also found that all the Macmillan Nurses questioned felt the six-month definition was restrictive.

Memorandum submitted by the United Brain Tumour Campaign

The United Brain Tumour Campaign is an amalgam of a number of small voluntary bodies and it has taken a time to agree this briefing note for me to pass onto you. It is hoped that it will be of use during the Session on 21 March in relation to improving the patient journey. It may also be helpful for 23 March on the NHS Cancer Plan. The patient journey in the case of brain cancer is often agonisingly delayed because GPs are for various reasons slow to suspect and diagnose brain tumour—this is particularly sad because brain cancer can often be remarkably quick to double in size and there is a premium on early diagnosis.

BRAIN CANCER BRIEFING FROM THE UNITED BRAIN TUMOUR CAMPAIGN (UBTC)

Sixteen thousand people a year are diagnosed with a brain tumour: 6,400 (40%) have primary tumours of the brain; the remainder have secondary tumours spread to the brain from primary tumours elsewhere. Around 25% of all cancers spread to the brain. The prognosis for children diagnosed with a brain tumour is poor. Those who are cured are often left with side effects and significant disabilities for the rest of their lives. The apparent low incidence means the brain tumour community broadly defined is poorly supported: funding for support and research is largely dependent on charities.

There are over 120 different types of brain tumour which present in different ways. With a diverse range of symptoms, diagnosis can take months causing stress and delaying the necessary treatment. Early diagnosis is desirable for what is often a fast-growing cancer and earlier attention may prevent acute complications in treatment later. Once diagnosed, it is difficult to find information and discover the options available. There is also a lack of specialised support in the medical and caring professions. And, at a time when quality of life becomes uppermost in a family's mind, stretched financial resources add further stress.

STATISTICS

- The true extent of the disease is unknown because of the limited capture of relevant statistics. Deaths from complications of brain tumours are often registered as other causes on the certificate.
- The many sources of information demonstrate inconsistencies and gaps.
- Brain and spinal cancers account for some 30% of childhood cancers: their occurrence has been rising over the last 10 years by 1–3% pa.
- Nearly 450 children a year are diagnosed with a brain tumour; and 100 children a year die as a result of a brain tumour. Brain tumours are the most common solid tumours now found in children.
- Brain tumours have overtaken leukaemia as the biggest killer of children under 15: survival rates for leukaemia have improved dramatically over recent years partly because of the amount of research funding devoted to it. Brain tumour survival has not improved so dramatically.

UBTC AIMS:

- **Education** for GPs and to establish clearer referral guidelines.
- **Information** for patients and carers.
- **Support** for patients and carers, emotional, physical and financial.
- **Specialised professional support** particularly adult and paediatric neuro-oncology nurses.
- **Research** into discovering the causes, advancing treatments and finding a cure.

Education for GPs and to establish tighter referral guidelines

- The 120 types of brain tumour cause a confusion of varied symptoms, often the same as for other illnesses. Brain tumours can be hard to diagnose—it sometimes requires persistence from patients and their families to insist that something is wrong. GPs should be made more alert to the potential of brain tumours to cause a variety of symptoms.
- Referrals for MRI scans can take weeks and in some cases years whilst GPs either do not recognise the symptoms or choose to eliminate other causes first.
- GPs and other medical professionals need information to be more widely available and to receive training regarding the differing symptoms of the various tumours.
- There are no cheap tests to reliably identify brain tumours short of an MR or CT scan and even here false positive and negative rates are poor.

Information for patients and carers

- There are leaflets, books and audio tapes provided by charities but resources are limited and in many cases they are out of date.
- There should be a dedicated easily accessible central repository of knowledge within the NHS or the web, reliable and comprehensible for laymen.
- The options and treatments available should be fully and consistently explained in all treatment centres, with risks for each option highlighted in simple terms eg what surgery is available, which surgeons will operate in cases that others won't etc. in the UK and elsewhere in the world; and, what drugs are available, what are the side effects, is there a clinical trial to participate in anywhere worldwide.
- People need to be better informed on what support is available/financial, physical and emotional, on the NTIS or charitable.

Specialised professional support particularly adult and paediatric neuro-oncology nurses

- The limited number of hospitals which treat brain tumour patients should each have a multi-disciplinary team approach—speech therapists, occupational therapists, epilepsy nurses, physiotherapists, nutritionists, social workers, neurologists, oncologists, neuro-surgeons and neuro-oncology nurses should work as a team; and, each relevant hospital should have at least one dedicated adult and one dedicated paediatric neuro-oncology nurse specialist. In Scotland and Wales there are no paediatric neuro-oncology nurse specialists. In addition, specialised therapy equipment in hospitals and at home, specialised counselling, night sitters and respite care should be available.
- Radiotherapy is not available at all centres and there is often an 8–12 week delay before treatment—often too late. Drug treatment during the waiting period is not always provided and there are too few new therapies under trial.
- Patients undergo incessant waiting periods, waiting for results, waiting for surgery, waiting for treatment to start. Clinicians are stretched and see brain tumour patients on certain days of the week as they focus on other conditions on the other days.
- There is a need for more specialist adult and paediatric neuro-oncology nurses in local communities and those that are available are often funded by charities.

Support for patients and carers, emotional, physical and financial

- Carers often need to give up work to provide full time care which can go on for years.
- The ideal would be to meet the needs and expectations of the patients and their carers with a holistic care package, rather than having to source social workers, benefits, information and support by themselves.
- Neuro-oncology nurses are in short supply and do not have the time to set up much needed support groups to offer counselling and help. They rely on patients, carers and charities to set these up. There are support groups but these have often been set up in isolation, are not readily available and are inconsistent in the support they can provide.
- Hospitals should provide facilities for families including overnight facilities, rest rooms and showers.
- Bereaved families should have freely available bereavement support.
- Patients and their families need access to an adequate system of psychological and moral support through the transition from surgery, recovery, acquired disability and acceptance.
- Funding is desperately needed for families who have to travel miles for treatment and often need to pay for accommodation, and hidden costs such as: parental leave, new clothes for children on steroids whose clothes no longer fit, special holidays to ease the pain, moisturisers and sun screens etc.

Research into discovering the causes, advancing treatments and finding a cure

- Brain tumour research needs a higher priority. Laboratory brain tumour research is carried out near only -10 brain tumour treatment centres. Pressure on university funding resulted in the recent loss of the research centre at Kings College, London. Clinical trials are undertaken in only half of the brain tumour hospitals.
- Scientists rely on the support of patients and families to set up charities and trusts in order to raise much needed funds for research.

- In some cases clinicians and scientists are working in isolation, resulting in a duplication of research activities. An integrated programme of research needs to be adopted, with the establishment of dedicated brain tumour research centres, focusing on particular fields.
 - Results of research activities are not widely distributed and shared to help people make informed choices: particularly regarding information on potential causes of brain tumours, including the safe use of mobile phones and risks, the potential links with viruses etc. Research results should be published and shared with all interested parties.
 - Ethical requirements can be unnecessarily burdensome—repeated form filing is distressing to patients and frustrating to researchers. Patients/parents have to sign consent forms at every step of the way—consent to operate, for pathological diagnosis, for tissues to be used for research etc. A study should be undertaken of how to simplify the system whilst still keeping adequate safeguards.
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