



House of Commons
Committee of Public Accounts

Delivering the Cancer Reform Strategy

Twenty-fourth Report of Session
2010-11

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

*Ordered by the House of Commons
to be printed 15 February 2011*

HC 667
Published on 1 March 2011
by authority of the House of Commons
London: The Stationery Office Limited
£11.00

The Committee of Public Accounts

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Eric Joyce (*Labour, Falkirk*)

Powers

Powers of the Committee of Public Accounts are set out in House of Commons Standing Orders, principally in SO No 148. These are available on the Internet via www.parliament.uk.

Publication

The Reports and evidence of the Committee are published by The Stationery Office by Order of the House. All publications of the Committee (including press notices) are on the Internet at <http://www.parliament.uk/pac>. A list of Reports of the Committee in the present Session is at the back of this volume.

Committee staff

The current staff of the Committee is Philip Aylett (Clerk), Lori Verwaerde (Senior Committee Assistant), Ian Blair and Michelle Garratty (Committee Assistants) and Alex Paterson (Media Officer).

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Summary

Each year in England, around 255,000 people are diagnosed with cancer and around 130,000 die from the disease. The NHS spent £6.3 billion on cancer services in 2008-09. Tackling Cancer has been a priority for the Department of Health (the Department) since its ten year NHS Cancer Plan was published in 2000. In 2007 the Department published its five year Cancer Reform Strategy (the Strategy) to deliver improved patient outcomes.

Over the last ten years, the NHS has made significant progress in delivering important aspects of cancer services, with falling mortality rates and consistent achievement of the cancer waiting times targets. Since publication of the Strategy in 2007, improvements have also been made in reducing the average length of stay and numbers of patients treated as day cases. A significant increase in resources has contributed to these improvements, but the progress has also been achieved through clear direction and high profile leadership underpinned by strong performance management linked to waiting times and mortality targets.

We welcome the Department's and NHS's commitment to improving the outcomes for cancer patients. We are concerned, however, that early diagnosis does not happen often enough; whilst cancer survival rates have improved and mortality rates have fallen, the gap in survival rates between England and the best European countries has not been closed. There remain wide, unexplained variations in the performance of cancer services and in the types of treatment available across the country.

It is disappointing that ten years after the publication of the NHS Cancer Plan 2000 there remain significant gaps in information about important aspects of cancer services, in particular information on chemotherapy, on follow-up treatment, and on the stage that a patient's cancer has reached at the time of diagnosis. The Department can not yet measure the impact of the Strategy on key outcomes, such as survival rates, and does not know if it is commissioning cancer services cost-effectively, due to poor data on costs and because outcomes data are not sufficiently timely.

We were surprised that value for money has not been a stronger focus for commissioners, both in securing services to meet the health needs of their local population or in assessing the performance of its suppliers. Few commissioners make best use of the information available and most do not know whether their commissioning is cost-effective.

The Department has recently refreshed its approach to delivering improvements in Cancer Services, with the publication in January 2011 of *Improving Outcomes: A Strategy for Cancer*. We consider it a priority that the Department should continue to improve information on cancer-related activities. We look to the Department to develop robust mechanisms to ensure the collection of high quality, comprehensive and timely data to raise awareness of cancer, provide transparency in the performance of commissioning

consortia, and ultimately drive improved outcomes for cancer patients.

On the basis of a Report by the Comptroller and Auditor General,¹ we took evidence from the Department on its and the NHS's performance in delivering cancer services; on improving information on activity, cost and outcomes of cancer services; and how the Department intends to deliver cost-effective cancer services in the new NHS.

¹ C&AG's Report, *Delivering the Cancer Reform Strategy*, HC (2010-11) 568

Conclusions and Recommendations

1. **We fully support the work that the Department has done over the last 10 years to make tackling cancer a priority. We welcome the progress made by the Department and NHS in reducing mortality rates and consistently achieving the waiting times targets.** We also note the National Audit Office's value for money conclusion that further improvements can be achieved by tackling variations in service delivery and raising performance to the standard of the best. The key driver of further improvements is the need for high quality, comprehensive and timely data that is understood and used to make decisions about how services should be configured. In the transition to a new NHS structure, the Department must maintain the momentum it has recently established in improving information on cancer-related activities. The recommendations that follow are intended to help the Department further improve delivery of cancer services and improve outcomes for cancer patients.

2. **Early diagnosis is still not happening often enough and this is reflected in poor one year survival rates for most cancers compared to other countries.** Whilst cancer survival rates have improved and mortality rates have fallen, the gap compared to the best performing countries in Europe has not been closed. The Department estimated that around 10,000 deaths from cancer could be avoided each year if the one year survival rates in England were the same as the best performing countries. Key to improving survival is improved awareness and early diagnosis.
 - We welcome the Department's plans to pilot and evaluate public awareness campaigns about the symptoms of cancer at a local and regional level. The Department should report back to us by the end of 2011 on the outcome of the pilots and the impact that raising public awareness of the symptoms of cancer has on achieving earlier diagnosis.
 - We are concerned that there is an eight-fold variation between GP practices urgently referring patients with suspected symptoms of cancer to specialists. We accept that there will be variation between GPs as some will choose to refer patients to specialists whilst other GPs will carry out their own diagnostic tests. However, the Department should ensure that commissioners investigate as a matter of urgency those GP practices that have both high and low referral rates and compare their referrals with their use of diagnostic tests.

3. **There remain wide, unexplained variations in the performance of cancer services and the delivery of treatment across the country.** There are wide variations in, and poor understanding of: the extent of emergency admissions; the use of urgent referrals; cancer screening coverage; the use of radiotherapy machines; and chemotherapy treatment. The Department should work with commissioners to get a firmer grip on the reasons for variations and what impact this has on patient outcomes. In order to reduce the risks of a postcode lottery in access to treatment and services, the Department should identify and implement clear and practical actions that can be taken to spread good practice quickly so that the worst

performing Primary Care Trusts (PCTs) can be brought up to the standards of the best.

4. **It is very disappointing that ten years after the publication of the NHS Cancer Plan 2000, there are significant gaps in information about important aspects of cancer services. The lack of information inhibits effective decision making and limits patient choice.** There are shortcomings in the availability, consistency, timeliness and quality of key data such as on chemotherapy which accounts for a fifth of the overall cancer budget. The Department lacks a coherent strategy to address these gaps and limitations. The Department should develop a cancer information strategy which includes common standards for the quality and timeliness of data on cost, activity and outcomes. It should clarify how it intends this information to be used to improve patient outcomes and to inform patient choice.
5. **A particular problem is the paucity of data in most regions about the stage that a patient's cancer has reached at the time of diagnosis.** This information, known as 'staging data', is key to making better use of resources and improving outcomes, yet only the Eastern region has anything like acceptable coverage. The Department needs to convey to cancer registries and, in turn, to clinical teams the value and importance of recording accurate staging data at the point of patient diagnosis. The Department should ensure that staging data is complete and timely in at least 70% of cases in each region by the end of 2012.
6. **The Department cannot measure the impact of the Strategy on key outcomes, such as survival rates, and does not know if it is commissioning cancer services effectively, because cost and outcomes data are not sufficiently timely.** Cancer registries should be required to provide data to the Office for National Statistics within six months of the end of the relevant calendar year to enable the Department to speed up the provision of comprehensive national and regional outcomes data to commissioners.
7. **Many commissioners do not do enough to understand costs and value for money in their delivery of cancer services.** We are concerned that only a fifth of PCTs had assessed the value for money delivered by their providers and that 12% had no plans to carry out such an assessment. In moving towards commissioning by GPs, the Department should work with the NHS Commissioning Board to set out clear standards requiring commissioners to demonstrate how they are obtaining value for money. The Department should say how it will measure improvements and what incentives and penalties will be used to ensure that value for money is at the heart of commissioning decisions.
8. **The numbers of cancer survivors is expected to increase from 1.7 million in 2010 to 2 million by 2020, yet the Department is unable to measure whether it is delivering on its commitment of more cost-effective provision of follow-up and care outside hospital.** The Department expects commissioners to identify more cost-effective ways of providing follow-up services to increasing numbers of cancer survivors and intends that meeting the increased demand for such services should be cost neutral. The Department should improve its information on outpatients and other forms of follow-up care by requiring such activity to be properly coded. The

Department should also identify and disseminate examples of good practice where savings and benefits to patients are identified and evaluate what impact alternative approaches to follow-up care have on hospital activity.

1 Tackling weaknesses in the delivery of cancer services

1. Each year, in England, around 255,000 people are diagnosed with cancer and around 130,000 die from the disease.² In the 1990s England suffered higher deaths rates from cancer and lower rates of long term survival than most other European Countries. In response, the Department of Health (the Department) published its NHS Cancer Plan in 2000 which set out a ten year strategy to improve cancer services.³ By 2007 although there were improvements in cancer services, the gap in survival rates between England and the best European countries had not closed. New challenges had also emerged including: rising incidence of cancer; increasing numbers of survivors requiring monitoring and ongoing care; and consequent pressures on cost and capacity. The Department therefore published a five-year Cancer Reform Strategy (the Strategy) to refocus its efforts and improve patient outcomes through prevention, early diagnosis and access to cost-effective treatments.⁴

2. The Department and NHS have made significant progress in delivering important aspects of cancer services, with falling mortality rates and consistent achievement of the cancer waiting times targets. Since publication of the Strategy in 2007, improvements have also been made in treating more patients as day cases and reducing the average length of stay.⁵ The Department explained that these improvements had been achieved as a result of a period of sustained increased investment which was used to increase staff numbers, improve facilities and invest in new equipment and drugs. It had also helped to have clear direction, national and local leadership, underpinned by strong performance management linked to waiting times and mortality targets. Evidence based guidance from the National Institute of Clinical Excellence, greater participation in clinical audits and the development of peer reviews had also assisted progress.⁶

3. Despite this progress, however, the gap in one year survival rates compared to the best performing countries in Europe had not been closed. The Department estimated that around 10,000 deaths from cancer could be avoided each year if the one year survival rates in England were the same as the best performing countries in Europe (Figure 1). It told us that if people in England survived for one year, their chances of surviving up to five years and beyond were roughly speaking the same as they would be in other developed countries. The Department acknowledged that poor one year survival rates were generally a sign of late diagnosis.⁷ Late diagnosis was a major problem with ovarian cancer for example, as it was a difficult cancer to diagnose. Survival rates were 38% compared with 79% for breast cancer.⁸

² C&AG's Report, para 1

³ C&AG's Report, para 4

⁴ C&AG's Report, para 6

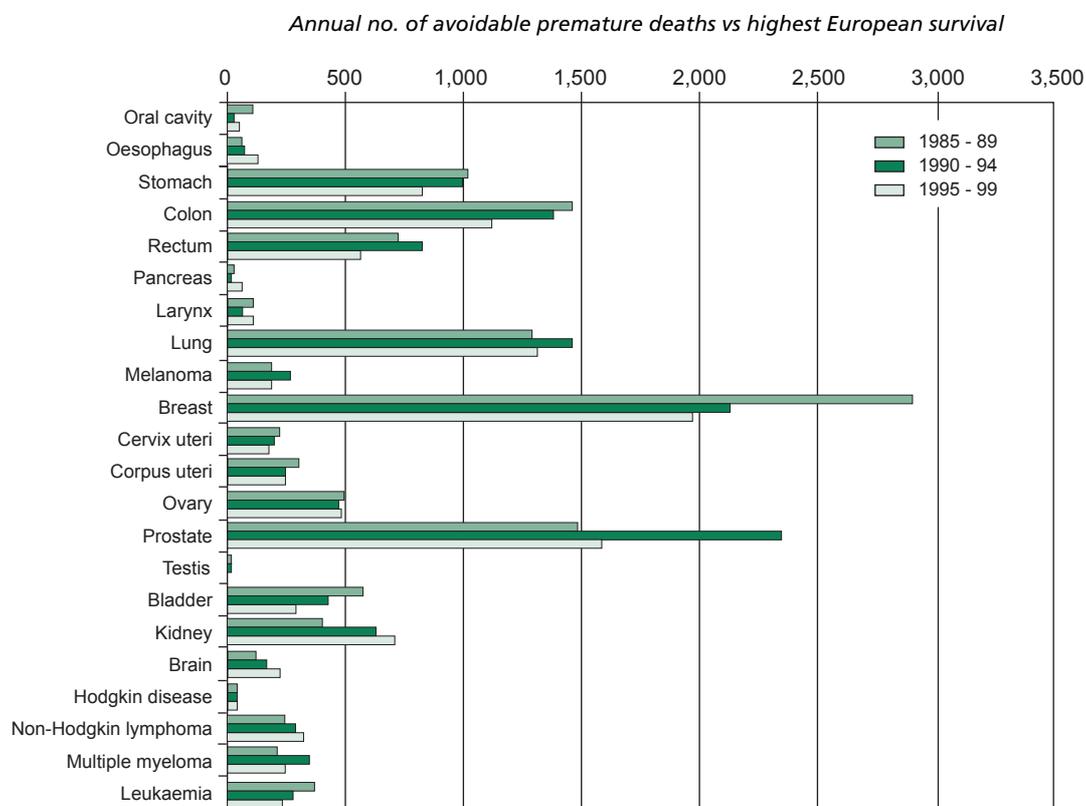
⁵ C&AG's Report, para 3, 17 and 23

⁶ Q 1

⁷ Qq 2, 8-10

⁸ Qq 12, 15

Figure 1: Annual number of deaths within 5 years of diagnosis that would be avoidable among cancer patients in Britain if relative survival were equal to the highest European survival for 22 common cancers¹



Note 1: patients diagnosed 1985-1999, 1990-1994, 1995-1999

Source: M Abdel-Rahman, D Stockton, B Ratchet, T Hakulinen and MP Coleman, "What if cancer survival in Britain were the same as in Europe: how many deaths are avoidable?" *British Journal of Cancer* (2009) 101, S115-S124

4. Key to improving survival rates are improved awareness and early diagnosis. The Department told us that it could do more to raise public and GP awareness of the symptoms of cancer.⁹ It did not have evidence of what worked in terms of awareness raising campaigns for cancer, but had evidence from other campaigns, including on stroke and diabetes, which it considered had been cost-effective. The Department saw no reason why such campaigns should not be effective for cancer. It told us it needed to build the evidence base of what worked and was planning to pilot and evaluate public awareness campaigns about the symptoms of cancer at both a local and regional level. If these pilots were successful, the Department would go on to do national campaigns.¹⁰

5. PCTs did not appear to be addressing the large variation in the rates of urgent referrals by GPs. In 2009-10, over 900,000 people with a suspicion of cancer were referred by their

⁹ Qq 14-15

¹⁰ Qq 16-17

GPs to specialists. Of these, 11% were diagnosed with cancer.¹¹ The National Audit Office found that there was an eightfold variation in the rate at which GP practices in England urgently referred patients with suspected symptoms of cancer to specialists.¹² The Department explained that there would always be variation as some GPs chose to refer patients to specialists and some carried out their own diagnostic tests such as chest X-rays and ultrasounds. The Department planned to feedback the figures on variations to GPs to enable them to benchmark themselves against others. It also wanted to be able to identify those GPs who were both low investigators and low referrers because it had concerns that they might be missing cases. Equally if GPs were high investigators and high referrers, they could be costing the system a lot of money.¹³

6. There remained wide, unexplained variations in the performance of cancer services and the delivery of treatment across the country. Data showed that the percentage of cancer patients treated with chemotherapy ranged from around 5% and 35% between PCTs. The Department felt that this degree of variation was implausible and that it was a problem of poor recording of data rather than demonstrating true variation.¹⁴ It told us it had carried out three separate surveys - in 2004, 2006 and 2008 - looking at variations in the use of chemotherapy across the country, and the surveys had shown that variation had reduced each time.¹⁵ There was also variation in the use of linear accelerator machines for radiotherapy treatment; ranging from 4,000 treatment sessions per machine to 10,000 despite a Departmental target that each machine must deliver 8,000 treatment sessions per year.¹⁶

7. The Department was planning to publish a large-scale survey reflecting what cancer patients think of their care. It expected that this would show variations across the country in whether patients had access to a clinical nurse specialist, whether they had enough information, whether they understood what was wrong with them and whether they had confidence and trust in their doctors and nurses.¹⁷ The Department told us it was working very hard to ensure that data on a whole range of cancer services, including one year survival rates, cancer screening rates, and emergency admission rates were fed back to PCTs so that they could see what their performance was and benchmark it against others.¹⁸

¹¹ Q 30; C&AG's report, para 2.16

¹² C&AG's report, para 2.18 and Figure 14

¹³ Q 30

¹⁴ Qq 18-19, 23; C&AG's report, para 1.13 and Figure 5

¹⁵ Q 23

¹⁶ Qq 34, 36-38

¹⁷ Q 33

¹⁸ Q 49

2 Better information on cancer services and their costs

8. The Department receives data from numerous sources including cancer registries, the Office for National Statistics and NHS hospital trusts.¹⁹ The Department established the National Cancer Intelligence Network in 2008 to improve the collection and coordination of cancer data by bringing together data specialists, organisations and datasets.²⁰ The Department hopes that the National Cancer Intelligence Network will enable data to be generated, turned into intelligence and used to improve patient outcomes. It believes that its cancer information system is currently on a par with other countries, but its aim is to be the best country in terms of cancer information, as it considers that information is the key driver to improving the quality of cancer services.²¹

9. Giving patients more choice is a priority of the modern NHS based on research which suggests that treatments are more effective if patients choose, understand and control their care.²² There are shortcomings in the availability, consistency, timeliness and quality of key data and the lack of information inhibits patient choice. The Department accepted that it needed to find ways to put the information about different hospitals and different PCTs into the public domain in a way that the public would find useful.²³

10. There is poor data on the use of chemotherapy which accounts for around a fifth of the overall cancer budget.²⁴ At the time of our Hearing, the planned chemotherapy database was two and a half years behind schedule, and reporting was not due to start until April 2012.²⁵ The Department accepted that the data was not as good as it should have been as some hospitals hadn't seen the value of recording data on chemotherapy. It considered that these data would improve once the chemotherapy dataset was in place and the data could be captured electronically at source. The Department told us that collecting better data on the use of chemotherapy would be a priority going forward.²⁶

11. The Department acknowledged that the paucity of data in most regions about the stage that a patient's cancer has reached at the time of diagnosis was an extremely important issue and resolving it was key to making better use of resources and improving outcomes.²⁷ There were eight regional cancer registries, of which the Eastern Cancer Registry and Information Centre was the best performer, capturing information on the stage that the cancer had reached when the patient presented to the NHS in 70% of cases. The North

¹⁹ Q 28; C&AG's report, Figure 7

²⁰ Qq 28, 49

²¹ Qq 46, 49

²² <http://www.nhs.uk/choiceintheNHS/Yourchoices/allaboutchoice/Pages/Allaboutchoice.aspx>

²³ Q 50

²⁴ C&AG's report, para 1.14-1.15

²⁵ Qq 20, 29 and 41

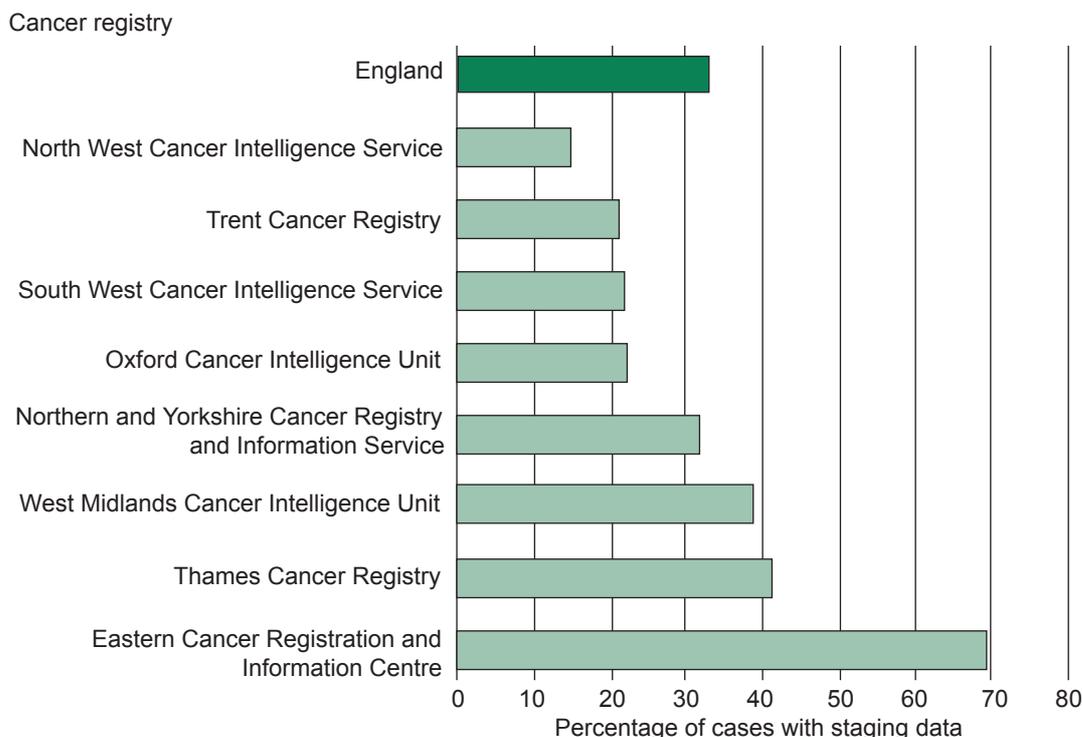
²⁶ Qq 19, 23, 29 and 78

²⁷ Qq 23-24, 26-27

West registry collected staging information in only 15% of cases (Figure 2).²⁸ The Department told us that it was working with the Eastern Cancer Registration and Information Centre to understand its processes in order to share this approach with other registries.²⁹ It believed that capturing good information depended on recording accurate staging data at the point of patient diagnosis.³⁰ The Department believed that to improve the frequency of recording of data it needed to explain what the data would be used for and how it would impact on the quality of treatment of patients.³¹ The Department acknowledged that improving such data was a priority and committed to improve the collection of staging data to the levels achieved by the Eastern Cancer Registration and Information Centre within two years.³²

Figure 2

Completeness of staging data in registries, 2007



Source: National Cancer Intelligence Network

²⁸ Q 47; C&AG’s report, para 1.1 and Figure 6

²⁹ Q 24

³⁰ Q 78

³¹ Q 41

³² Qq 100-102

12. The Department can not measure the impact of its Strategy on key outcomes, such as survival rates. It does not know if it is commissioning cancer services cost-effectively, because outcomes data are not sufficiently timely. The Department told us that there had been major improvements: five years ago outcomes data took up to three years to obtain but was now taking on average 18 months. It considered that 18 months was on a par with other cancer registries around the world but that the Eastern Cancer Registration and Information Centre had demonstrated that it could be done within six months. It commended this registry for the efforts it had made and said that it was time for the other cancer registries “to catch up”.³³

13. The Department’s Programme Budgeting data indicated that spending on cancer services had increased from £3.4 billion in 2003-04 to £5.1 billion in £2008-09.³⁴ This figure was £1.2 billion (19%) less than the more inclusive estimate of £6.3 billion that the National Audit Office calculated was spent on cancer services in 2008-09. The difference in the two figures was because Programme Budgeting data showed what was spent on cancer patients once they had been diagnosed, whereas the £6.3 billion included wider costs, such as screening and other diagnosis related activities. The Department welcomed the NAO’s more comprehensive estimate of the costs of providing cancer services in England.³⁵

14. Many commissioners do not do enough to understand their costs and most do not know whether their commissioning is cost-effective. Just 22% of PCTs had attempted to assess the value for money delivered by cancer service providers and 12% had no plans to do so.³⁶ Most did not link cost and activity data to incidence, prevalence and survival data.³⁷ PCT expenditure on cancer services varied from £55 to £154 per head in 2008-09, and 54% of this variation could not be explained.³⁸ Despite being a focus of the Strategy, only around half of PCTs had identified where expenditure which did not benefit the patient could be eliminated, and just 20% could demonstrate quantified efficiency gains as a result of implementing the Strategy.³⁹

15. The Department expressed the view that PCTs were focussing on value for money across the whole spectrum of services they commissioned rather than specifically looking at value for money from a cancer perspective.⁴⁰ It said that since the ‘world-class commissioning’ initiative was introduced there had been incremental improvement in commissioning. Audit Commission assessments of the financial management of PCTs had shown significant improvements over the last three years, although the number rated “red” had increased slightly between 2008 and 2009.⁴¹ The Department accepted that PCTs

³³ Q 43

³⁴ C&AG’s report, para 3.2

³⁵ Qq 34-35, 62; C&AG’s report, para 3.2 and Figure 15

³⁶ Q 56; C&AG’s report para 2.11

³⁷ Q 89; C&AG’s report, para 14

³⁸ Q51; C&AG’s report, para 2.5 and 3.3

³⁹ Q 52; C&AG’s report, para 13

⁴⁰ Qq 52, 61

⁴¹ Q 58-59

needed to look specifically at value for money in cancer services and that there were areas where they could make savings and improve quality of care.⁴²

⁴² Qq 55, 73; C&AG's report, para 2.11

3 Applying lessons in the new NHS

16. Improvements in cancer services will need to be delivered in the face of tighter finances, increases in the number of new cases each year, and against a background of considerable change in the NHS. In July 2010, the Secretary of State for Health asked the National Cancer Director to review the Strategy to determine if it was the right strategy to deliver improved cancer survival rates. The NAO found that there was a risk to the successful delivery of any future strategy unless there was considerable improvement in the information used to support its implementation. It recommended that the Department should develop an action plan which identified the roles, responsibilities and timelines for taking actions.⁴³

17. In January 2011, after our hearing, the Department published its new approach to delivering improvements in cancer services *Improving outcomes: A Strategy for Cancer*. It told us that the new Strategy would be aligned with the direction set in the July 2010 NHS White Paper, *Equity and Excellence: Liberating the NHS*.⁴⁴ The Department told us that the main drivers which would deliver improved survival rates were: better use of information; more emphasis on outcome measures rather than processes; effective commissioning arrangements; and reducing the incidence of cancer through prevention measures, screening and raising public awareness of the symptoms of cancer.⁴⁵

18. Within the context of considerable change in the NHS and the transfer of commissioning responsibility from PCTs to GPs, the Department assured us that it had the levers in place to get better data, and set out how it would secure the improvements (Figure 3).⁴⁶

Figure 3

The Department's approach to data in the new NHS

"The White Paper is very clear that the setting of standards for data in the health service will sit with the NHS Commissioning Board. There is an expectation that this single point of accountability will define the standard and it will be a requirement for providers in the system to surface data to that standard. This should make things move faster than they have previously and with some clarity on who has got to do what, by when, in terms of providing data to that standard.

When a provider surfaces that data, there are a number of different things it can then be used for. An individual patient's information could flow back to the patient from an acute trust to the GP. The White Paper and then the subsequent consultation on the Information Revolution are clear that we would expect to collect the data in an aggregate form once through the information centre. The Information Centre would be expected to publish that data and allow other third parties to use it and present it to different groups in ways that may be more meaningful for them.

We would expect to see much more data published and in the public domain, the source of it coming out of the health service, but various interpretations that would help people, patients particularly, to exercise their choice in an informed way and help people to then ask more questions of the system as a whole. We would also expect that aggregate data to be used by commissioners

⁴³ Q 75; C&AG's report, para 24

⁴⁴http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_117353

⁴⁵ Q 75

⁴⁶ Q 77

to take a view of their population as a whole to help define and design services that would make sense for that particular population, and we would expect cancer services to be part of that.”⁴⁷

19. The numbers of cancer survivors is expected to increase from 1.7 million in 2010 to 2 million by 2020. Follow-up care for survivors has typically been through routine outpatient hospital appointments. The Strategy identified that the increase in survivors would necessitate improvements in the management and commissioning of follow-up care, and estimated that up to £240 million could be saved between 2008 and 2018 if improvements in follow-up care were made.⁴⁸ The Department told us that it believed meeting the increased demand should be cost neutral.⁴⁹ It expected to achieve this through commissioning more cost-effective follow-up care that would meet the needs of patients, including reducing routine follow-up and providing care in the community.⁵⁰ The Department was, however, unable to measure whether it was delivering on its commitment of more cost-effective follow-up care as it did not have information on the reasons for an outpatient appointment (whether it was during treatment or for monitoring purposes, or even whether the patient had cancer) as 97% of outpatient data was not coded.⁵¹

20. The Department has a National Cancer Survivorship Initiative which is focussing on the phase after patients have received primary treatment when the NHS is working with patients to help them back to as normal and healthy life as possible. The Department told us that, in the past, it had tended to have a one-size-fits-all model of follow-up whereby patients would have outpatient appointments every three months for the first year, then every four months, then every six months. The Department believed a lot of that follow-up was not providing the care that patients either needed or wanted. The Department was working in partnership, particularly with Macmillan Cancer Support, to look at what patients wanted in terms of follow-up care and to give patients the best chance of survival.⁵²

⁴⁷ Q 77

⁴⁸ Q 39; C&AG’s report, para 20 and 3.13

⁴⁹ Q 99

⁵⁰ Qq 92, 99

⁵¹ Qq 39, 81; C&AG’s report, para 3.14

⁵² Qq 92, 99

4 Formal Minutes

Tuesday 15 February 2011

Members present:

Rt Hon Margaret Hodge, in the Chair

Mr Richard Bacon

Jo Johnson

Mr Stephen Barclay

Nick Smith

Matthew Hancock

Ian Swales

Chris Heaton-Harris

Draft Report (*Delivering the Cancer Reform Strategy*) proposed by the Chair, brought up and read.

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

Paragraphs 1 to 20 read and agreed to.

Conclusions and recommendations 1 to 8 read and agreed to.

Resolved, That the Report be the Twenty-fourth Report of the Committee to the House.

Ordered, That the Chair 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.

Written evidence was ordered to be reported to the House for printing with the Report.

[Adjourned till Tuesday 1 March at 10.30 am

Witnesses

Tuesday 7 December 2010

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David Flory, Deputy Chief Executive and Director General Finance, **Christine Connelly**, Chief Information Officer and **Professor Sir Mike Richards**, National Clinical Director for Cancer and End of Life Care

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Tenth Report	Managing the defence budget and estate	HC 503
Eleventh Report	Community Care Grant	HC 573
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Twenty-second Report	Excess Votes 2009-10	HC 801
Twenty-third Report	The Major Projects Report 2010	HC 687

Oral evidence

Taken before the Committee of Public Accounts on Tuesday 7 December 2010

Members present:

Mr Richard Bacon (in the Chair)

Stephen Barclay
Chris Heaton-Harris
Joseph Johnson

Austin Mitchell
Nick Smith
Ian Swales

Michael Whitehouse, Chief Operating Officer, National Audit Office, **Robert Prideaux**, Director of Parliamentary Relations, National Audit Office, **Karen Taylor**, Director, National Audit Office, and **Marius Gallaher**, Alternate Treasury Officer of Accounts, were in attendance.

Examination of Witnesses

Witnesses: **David Flory**, Deputy Chief Executive and Director General Finance, Department of Health, **Christine Connelly**, Chief Information Officer, and **Professor Sir Mike Richards**, National Clinical Director for Cancer and End of Life Care, gave evidence.

Q1 Chair: Welcome to this morning's meeting of the Public Accounts Committee in which we're looking at the NAO report on Delivering the Cancer Reform Strategy. We're joined by Professor Sir Mike Richards, who is the National Clinical Director for Cancer and End of Life Care, by Christine Connelly, the Chief Information Officer for Health, and by David Flory, the Deputy Chief Executive of the NHS and Director General for Finance, who only found out he was coming to this hearing yesterday evening, I think, because of the illness of Sir David Nicholson. So we wish him well and hope he recovers soon. Sir Mike, may I start by congratulating you on your knighthood, because you've appeared before this Committee on a couple of previous occasions at least, but not since you've been knighted, which I think is some testament to the work that you've been doing. We all feel the Department should be congratulated for the progress that has been made, because there definitely has been some progress. We want to focus in this hearing on where further improvements should be made and where they are capable of being made, but first can you start by telling us what factors have led to your achievement so far.

Professor Sir Mike Richards: Thank you very much indeed for that introduction; that's extremely kind. I think a whole range of different factors have led to the progress that we've made in this country on cancer over the past 10 to 15 years. We have of course had a period of sustained investment. That's been extremely important in terms of making sure that we have the staff we need, the facilities, the equipment and indeed the drugs, and so we have seen investment in cancer going up. Broadly speaking, investment in cancer's been going up in line with other disease areas. I think that having a clear direction, and I think that was set first of all in the Cancer Plan back in 2000 and then more recently in the Cancer Reform Strategy in 2007, helps to mobilise everybody and get them pointing in the same direction. I think leadership is important both at national level but also at the network level and at the local hospital level as well. We have improved the

collection of data and information, and I'm sure we'll come back to that, but we recognise there's a lot more to be done but that has also helped. Of course some of the achievements in the past decade have been made in the area of targets and performance management, and I certainly think for waiting times that was extremely valuable and we have made really very significant progress on waiting times. But there are other influences as well: the guidance that NICE has produced, the peer review programme, all of those collectively have helped us to make progress on cancer.

Q2 Chair: We still though have poorer survival rates than many other European countries. What does that tell us about the role of early diagnosis?

Professor Sir Mike Richards: Well, I think it does tell us how important early diagnosis is. When we have looked at our survival rates and compared them with other countries, what strikes us very clearly is that it is our one-year survival rates that are poor and that is generally taken to be a sign of late diagnosis. If people in this country survive for one year, their chances of surviving up to five years and beyond are roughly speaking the same as they would be in other developed countries. So I think we can focus on a late diagnosis as the major issue, as indeed we have started to do since the Cancer Reform Strategy in 2007.

Q3 Chair: One of the key issues of the strategy was to try to reduce emergency admissions and yet emergency admissions have continued to go up. One of the most worrying aspects of this is that a significant slug, about 20%, of diagnoses occur at emergency admission. Now what are you doing about that?

Professor Sir Mike Richards: Can I take those two as separate points? I think first of all the point about emergency admissions going up: yes, they are still going up. They were going up as the report says by 3.8% per annum and that has now slowed to 2% per annum; the incidence of cancer is going up by 1.6%

and the actual number of people alive with cancer is going up even faster than that, by over 3% per annum. So we've probably just about reached a plateau now. Now, that's not good enough. We need to get the emergency admission rate down, so I'm not in anyway complacent about that, but I think we have halted the rise to a large extent.

Q4 Chair: Why has it continued to go up in the last 10 years when it was almost point one of the strategy that it should go down, because plainly, planned admissions are easier to deal with?

Professor Sir Mike Richards: It was point one of the Cancer Reform Strategy, which was in 2007.

Chair: The refresh.

Professor Sir Mike Richards: Yes. Well, the second of our strategies. We had the Cancer Plan in 2000 and the Cancer Reform Strategy in 2007, and we are now refreshing that Cancer Reform Strategy. But we didn't focus particularly on inpatient care in the original Cancer Plan. We focused a lot of attention on getting patients from referral by a GP to a properly designated specialist team; we established the teams; where we needed to, we concentrated the teams in hospitals where they would have enough patients to become really expert at it, and we obviously focused on waiting times. It's since 2007 that we have been really focusing our attention on efficiency and productivity.

Q5 Stephen Barclay: Could I just follow up on that point in terms of the gap between where we are now 10 years into the strategy and where the best European country is. If we look at women's cancer survival rates in particular, I was surprised to learn that in 2003 I think we were 12th out of 22 countries in Europe. But by 2010, we were 23rd out of 27. Is that purely down to lifestyle issues or can you give some clarity around what is happening in terms of our position against other countries?

Professor Sir Mike Richards: I suspect that is also coming from the additional material that I know the NAO has supplied to you as well as to me. I think what you're referring to in fact is a death rate rather than survival. I know it sounds technical but the two are different. Mortality takes account of both the number of new cases in the country and how well people survive. The number of new cases obviously depends a whole lot on things like smoking incidence, so public health issues. Now, where we are on women's mortality is that, unfortunately, smoking went up in this country in women rather before it did in other countries. If you take both men and women, it is often said that in men the rise of smoking in this country really happened following the First World War, and the rise of smoking in women happened after the Second World War or at the time of the Second World War. You then see the peaks of cancer, such as lung cancer, about 20 years after that. So we are now seeing the peak of lung cancer in women. I hope that will now turn down again. I'm afraid other countries, because they are still on the upward slope of smoking, will see a rise in their mortality, so I think we can be relatively confident that in terms of our female mortality we will start improving again, but that is largely driven by two things: it's driven by lung

cancer mortality, which is smoking, it's also related to breast cancer mortality, where 20 years ago we were the worst in the world. We had the highest mortality from breast cancer of any country. We have since then had the steepest decline in breast cancer mortality, which I think suggests we're doing some things right. But at the moment, it's that combination of breast cancer and lung cancer that's driving the figures you mention.

Q6 Stephen Barclay: Right, because the trend is going the wrong way and we had the previous hearing on health inequalities, which found that, despite the Department addressing health inequalities as a key priority, health inequalities actually widened in recent years. You mentioned the survival gap and the fact that it was improving on breast cancer, but just looking at your own figures from a presentation you gave in February 2010, it had 1,967 deaths from breast cancer that were avoidable if we compare England with the European best. What would it be if we were to look across cancers as a whole? How many avoidable deaths are there from cancer in this country if we compare ourselves with the European best?

Professor Sir Mike Richards: Well, that figure of 1,967 breast cancer avoidable deaths comes from a paper that was published in the *British Journal of Cancer* in December last year by a colleague of mine, Professor Michel Coleman, and I absolutely stand by that.

Q7 Stephen Barclay: Well, it's your presentation.

Professor Sir Mike Richards: My presentation of his data.

Q8 Stephen Barclay: I'm reassured.

Professor Sir Mike Richards: Overall we estimate that if you put all cancers together there are around 10,000 avoidable deaths per annum.

Q9 Stephen Barclay: What, women, or combined?

Professor Sir Mike Richards: No, all cancers, both men and women.

Q10 Stephen Barclay: So there's 10,000 people in this country dying who if they were in another European country would be living?

Professor Sir Mike Richards: If they were in the best European countries.

Stephen Barclay: Yes.

Professor Sir Mike Richards: We defined best by taking the countries whose data we could rely on—we excluded countries where we didn't think the data were reliable—and we took the average of the top three with reliable data to make that estimate. So, with that, yes, if we brought ourselves up to that standard, we would save 10,000 lives a year.

Q11 Chair: On that point, the spending has now gone up to the European average level, hasn't it?

Professor Sir Mike Richards: It is extremely difficult to compare expenditure on cancer. I'm sure we'll come on to the difficulties in measuring expenditure on cancer later on. But it is therefore extremely difficult to compare expenditure on cancer between

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countries. What we can say is what the expenditure on health is. What we do know is we have narrowed the gap in terms of expenditure on health as a whole, and we know, broadly speaking, that our expenditure on cancer has gone up in line with our expenditure on health.

Q12 Nick Smith: Sir Mike, I recently had a note from one of the ovarian cancer organisations and they were concerned about the issues of early diagnosis and particularly around awareness raising and the success or not of awareness raising campaigns run by the Department. Can you tell a bit more about that please?

Professor Sir Mike Richards: Yes. If you go back to the same paper about avoidable deaths, of the 10,000 that I was mentioning, just under 500 are due to ovarian cancer. So we do think that late diagnosis is a major problem with ovarian cancer. It's a difficult cancer to diagnose; the average GP will see one case of ovarian cancer approximately every five or six years. The symptoms of ovarian cancer are not very obviously gynaecological. Quite often, people can have gastro-intestinal symptoms like bowel upset, or they can feel full very easily after a very light meal, or they can have urinary symptoms; it's a whole range of different symptoms and so it is very difficult to spot this. But what we are extremely keen to do is to work with GPs to make them aware of that constellation of symptoms, because in the past—for example, when I was a medical student—it was always referred to as the silent killer; people thought that there were no symptoms until it was too late. We now know that that's not right and so we've got to get the message across, particularly to GPs but also to the public, that there are these symptoms and that if they're persistent—that's the important thing—then they should seek medical help. They should then either have an ultrasound examination or a relevant blood test or be referred to hospital.

Q13 Chair: Ovarian Cancer Action, which has written to the Committee, says that survival rates, where it's detected early, can be as high as 90%. It goes on to say that women often mistakenly believe ovarian cancer will be detected by a cervical smear. It makes me wonder how many GPs mistakenly think that ovarian cancer can be detected by a cervical smear. Do you know what the state of knowledge is among GPs?

Professor Sir Mike Richards: I do very much hope that they would not think that ovarian cancer could be detected by a cervical smear. I really don't think that's likely.

Q14 Chair: But are they making sure that their patients understand that?

Professor Sir Mike Richards: I think we can all do more to raise awareness of the symptoms of cancer. I think GPs do have an important part to that and I think national campaigns, local campaigns, all of that, play a part as well.

Q15 Chair: Again in the note from Ovarian Cancer Action, what's striking is that the survival rates

haven't improved for 20 years and remain at 38%, although it's increased to 79% for breast cancer. So whatever has been done so far hasn't really worked, has it?

Professor Sir Mike Richards: I think the survival rate has improved, but not markedly. So I would take issue with the fact it hasn't improved at all, but I would certainly say it hasn't improved as much as I would like it to and I think we could see a significant improvement if we improved the early diagnosis. To that, we have to get both awareness in the public and awareness from GPs.

Q16 Nick Smith: On that point, what do you think about the success of awareness raising in the round in the general public around cancer?

Professor Sir Mike Richards: I think we haven't done enough of it and we are about to do a whole lot more. We have already announced that we will be doing more, particularly in the New Year. We are doing it both at a local level, and I think over 100 of the 152 PCTs are engaged in this, and we're also doing a pilot of a regional awareness campaign. We're targeting that on two regions, the east of England and the South West, because we want to learn what that sort of region-wide initiative would do. If that is successful we would want to go forward and do national campaigns.

Q17 Nick Smith: Awareness raising is expensive; buying any media is expensive; training professionals is expensive, I know. Do you know what works in terms of awareness raising for cancer?

Professor Sir Mike Richards: The honest answer to that is there isn't enough evidence, which is why we are seeking to build the evidence as we go. We will be evaluating both the local pilots and these regional pilots, which is why we haven't gone to a national campaign without getting that evidence. If you look across the world—and I can assure you that we have looked at all the evidence—the evidence isn't there for cancer. Having said that, I think we do have evidence that other campaigns, whether it's on stroke, on diabetes, on a whole range of other conditions, are effective and are cost-effective, so I see no reason why they shouldn't be effective for cancer. It's just that we do need to build that evidence base.

Q18 Austin Mitchell: I just want to move on to chemotherapy because my wife who was diagnosed with cancer had chemotherapy earlier this year and it seemed to me a treatment so horrible that it's a question of whether it kills the patient before the cancer or vice versa. I see alarmingly from the report that there's a wide variation in the use of chemotherapy and that figure 5 on page 17 says that the use of it ranges from 5% to 36%¹ between Primary Care Trusts. So first of all why is that?

Professor Sir Mike Richards: Two comments: first of all chemotherapy can be horrible. I was a medical oncologist myself; I was responsible for giving chemotherapy. I would also like to say that now we

¹ C&AG's report states "the percentage of cancer patients recorded as receiving chemotherapy ranged from around 5 per cent to 35 per cent", para 1.13

do have a lot better treatments—for example, anti-sickness medications—and so I think it's much less horrible than it used to be. I'm not denying it can be horrible. We do of course have very good evidence that it does extend life and it can in some cancers cure cancer, so we wouldn't be giving it unless we had that good evidence. In terms of the variation, frankly, I think that degree of variation is implausible. I'm quite sure the data are what the data say they are.

Q19 Austin Mitchell: Well it's not implausible to those who are getting it or not getting it.

Professor Sir Mike Richards: It is implausible to me that there are PCTs where less than 3.5% of patients are getting cancer and at the other end there are 31%. I think this is a coding problem and I think this is highlighting the need for better information. So I think figure 5 is really there to show this is implausible and it's part of the inexplicable variation that we have with a lot of data. We've got to get tighter on the data. This, to my mind, is much more likely to be a data problem and one therefore that we will now work with those PCTs that are identified from this to see what the problem is in recording.

Q20 Austin Mitchell: Okay, but there does seem to be a real problem with the data, information, about chemotherapy in the sense that the planned database is two and a half years behind schedule. The reporting will not now start until April 2012 and chemotherapy is used in different ways. Now, if you don't have the information about the use of chemotherapy and about its effectiveness, how are you going to decide where it's right to use it, because I have to say, one of the doctors told my wife it wasn't necessary, after she'd been through all that.

Professor Sir Mike Richards: In terms of being able to tell an individual patient whether it's necessary, we based that on the evidence from clinical trials.

Q21 Austin Mitchell: But is it just given a kind of routine? This is something you've got to do?

Professor Sir Mike Richards: Not at all. It's very different for different cancers. For example, there's very strong evidence in breast cancer that it improves survival rates; for diseases like testicular cancer or lymphoma it can make the difference between life and death in terms of curing the cancers. Other cancers, it will extend life by perhaps a few months, but not more than that. We've got very strong evidence from clinical trials on that, and indeed we have one of the best clinical trials set-ups in the world. The proportion of our patients that are going into clinical trials is higher than in any other country in the world, so I think we can be very proud of that.

Q22 Chair: I'm going to bring in Ian Swales on this point.

Professor Sir Mike Richards: Okay.

Q23 Ian Swales: Can I just stick with figure 5 and also refer to figure 6 over the page as well, because what we're seeing from those two is, if you like, the postcode lottery is suggested by these two figures, in the sense that if one gets cancer in one PCT there's

about a 30% chance of being treated with chemotherapy, and in another, it's less than 5%. Over the page the staging data that's kept appears to vary drastically between areas. I just wonder why that's allowed to be tolerated and to what extent best practice is shared quickly around the system.

Professor Sir Mike Richards: There are two points there. One is about the variation in chemotherapy, which, as I've already said, I genuinely think is a data problem. The evidence I have for that comes from another route we have to look at chemotherapy usage, a source called IMS Health, which collects data on the amount of drug that is given in different hospitals across the country. We have done three separate surveys: one in 2004, 2006 and 2008, looking at variations in the use of chemotherapy across the country and what we have seen from that is that the variation has reduced each time that we have measured it subsequently. So I think that the variation in chemotherapy is not as shown here; this is a data problem that we need to get on top of.

Q24 Ian Swales: So where would these data have come from?

Professor Sir Mike Richards: It is undoubtedly what hospitals have recorded. I'm not disputing that for one moment. This is as recorded, but this is an example of poor recording of data that we need to pick up on. Your other point was about the completeness of staging data. This is an extremely important issue; this is whether data on the extent of a patient's disease at the time of diagnosis is recorded in the cancer registries. Again, as you will see, there is one cancer registry that is doing a great deal better than the others, and we have been working with the Eastern Cancer Registration and Information Centre to look at what their processes are, and they get data in from multiple different angles. They get it in from pathology laboratories electronically; they get it from multidisciplinary teams; they get it from the National Cancer Waiting Times Database—all sorts of different data. They then have people who analyse those data and record the code from all those data at the centre. Now, what we are saying is if Eastern region can do this so can the others, and within the last few months, I have been talking to the other registries and agreeing with them that over the next one to two years we really do have to sort this staging issue.

Q25 Ian Swales: Final question on this: is there evidence that this registration does impact on outcomes, treatments, mortality, all those sort of things? Is there a direct link between this and what happens to patients?

Professor Sir Mike Richards: Our cancer registration in terms of do we get the information in and do we know the survival of patients, I am completely confident that we do. Now, do we get the extra data that I would like to see on the extent of disease, the staging? No, we don't, as this shows. So we can improve.

Q26 Ian Swales: My question was is there a link between the fullness of this data and the efficiency of this data collection and outcomes for patients?

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Professor Sir Mike Richards: No, there isn't, but if we had better information, we can drive the system better. Information is one of the key levers for driving up quality, so that's why it is such a priority, and it's why we identified it as a priority in the Cancer Reform Strategy of 2007.

Q27 Ian Swales: So you don't see significantly better data in terms of outcomes, etc, in the Eastern region, compared with the other regions?

Professor Sir Mike Richards: That's a very good way of putting it. If you look at the survival rates for people in the Eastern region they are almost identical with those for the rest of the country, but it would be easier to drive improvement in that part of the country, because they've got the staging data.

Ian Swales: Okay.

Q28 Chris Heaton-Harris: On this, I wonder whether you could take us through the process of where the Department receives data from awareness raising, through someone noticing the problem, going to the GP, the referral, the treatment, whatever. Where does the Department receive the data that it assimilates and how does it use that information and what other data is out there that you could possibly use?

Professor Sir Mike Richards: Well, part of that is set out in figure 7 on page 19, the different data sources, because data come from multiple different angles, so the cancer registries—and there are eight cancer registries in England and then one for Wales, Scotland and Northern Ireland—receive data largely from hospitals. That's their main source, and over the past few years they have got their data far more in electronic form, whereas in years gone by it was largely paper-based, sending out tumour clerks to go to hospitals to find the data. So it's far more electronic now, which I think is one of the reasons why we can be confident that the quality of cancer registration has gone up. So that's one data source.

The second data source is death rates, mortality. Every death certificate in this country has a cause of death on it. That goes to the Office for National Statistics and that information comes in very quickly after death. From a combination of the cancer registries and the ONS, we calculate the survival rates. A lot of the treatment data and the hospital activity data comes to us from Hospital Episode Statistics, the NHS information centre collects that information; so information on the length of stay, the number of admissions, the bed days, all comes from that source. What we have done is try to bring all these data sources together through this thing that we've called the National Cancer Intelligence Network, which we set up as a result of the Cancer Reform Strategy and it first came into being just over two years ago. It's partly about the data sets, the techie side of it; it is also about getting the people together. It's getting the experts, the clinicians, all the people who can work on making sense of those data, and that's what we're doing through the National Cancer Intelligence Network.

Q29 Chris Heaton-Harris: Are you confident that the data that are going into this system are consistently entered across the system, and then—you're developing this system—where are the gaps and where are the improvements to be made?

Professor Sir Mike Richards: For most of it, I am very confident. I am confident that if we do miss cases of cancer completely it will only be, at most, 1% to 2%. Even that I think is unlikely now. It has been more than that in the past. I am confident in the mortality data; I'm confident in the survival data; all of that. I'm confident of the data that we get through Hospital Episode Statistics, particularly in terms of inpatient episodes. That bit of it is good.

The areas that I have less confidence in are the ones you've already identified: the data on chemotherapy coding I don't think has been good. Hospitals haven't seen the value of recording it, so they haven't been recording it very well. We are pushing to get it recorded better. It will get a lot better when we have the chemotherapy data set. I think I know which information sources are utterly reliable and which are not, and we try to base our judgments only on those that are reliable and then to improve the other ones. And the two areas that I most want to improve are the ones that have been mentioned: chemotherapy and staging data. After that we can do better on pathology data, and we can do better on co-morbidity data; what other illnesses the patient has as well as cancer. But those are things that we can work on. The priorities are chemotherapy data and staging data.

Q30 Joseph Johnson: I was very struck by your comments about it being our one-year survival rates that are really poor and that once you get past the one-year threshold our survival rates fall into line with the best in Europe. On that point, as you said, it's linked to late diagnosis and I'm concerned at the NAO's finding that there were very large variations in rates of urgent referrals by GPs. An eightfold variation between GP practices in England and the NAO report suggests that PCTs in fact have taken no action to address this very substantial variation. So, first of all, is this a problem with the data again? Is there really this eightfold variation in your experience and, if there is, why haven't we done something about it?

Professor Sir Mike Richards: Yes, I do believe that data. That data comes from the National Cancer Waiting Times Database. Every month, we collect information on the numbers of patients who are referred urgently by their GP. There are overall about 900,000 people referred urgently with a suspicion of cancer in a year. There is a wide variation by GP practice and we are looking into that. We're doing a number of different things. First of all, we want to be able to feed that back to the GP practices, which we are now doing, so that they can benchmark themselves and say, "Oh gosh; I'm a low referrer," or "I'm a high referrer."

I think you also need to see this from a GP perspective. Some GPs will probably make more use of diagnostic tests—chest X-rays, ultrasounds etc—others will choose to refer. Now what I want to be able to do is to be able to look at those in parallel. Are they using diagnostic tests? Are they referring? If

you like, we want to be able to identify those GPs who are both low investigators and low referrers, because I would have concerns that they might be missing cases. Equally, on the other hand, if doctors are very high investigators and high referrers, they're probably costing the system a lot of money.

Q31 Joseph Johnson: Are there pockets of the country that are particularly concerning you on both counts at the moment?

Professor Sir Mike Richards: In terms of low use of the two-week wait urgent referral, when we look at that it is across the country that we see there are some PCTs that have lower rates and higher rates, but we published in the second annual report on the strategy the fact that those PCTs in London tend on the whole to have low rates of using the two-week wait.

Q32 Joseph Johnson: And why is that?

Professor Sir Mike Richards: Well, we've asked the London SHA and the London PCTs to look into that, and what we want to be able to do is to marry that up with whether more patients are coming in as emergencies in London. We are working on doing that at the moment. But I think it's important to recognise it is because we've got the National Cancer Intelligence Network that we've got access to this data. With the new information about the fact that 23% of patients present as emergencies, we've only been able to do that because we have been able to link the data on how patients come into hospital with their survival rate. That's only within the last three or four months that we've had that data, which obviously we also shared with the NAO.

Chair: I want to bring in Steve Barclay briefly on data quality and then shortly I want to move on to spending.

Q33 Stephen Barclay: I was a bit puzzled, Sir Mike, by your answer to Ian Swales, because surely survival rates are not the only measure of quality? How are you defining the measurement of quality? For example, I would have thought symptom reduction is a measure of quality as well, and what I can't understand is, if you have 11 years into your tenure such gaps in data—for example, 97% of outpatient appointments are not coded—between PCTs, how do you know whether the outcomes are just a result of poor collation of data or poor data quality or because your money is not being spent wisely?

Professor Sir Mike Richards: Well, as I said, I think we do know which aspects of data we have got good quality on and which ones we haven't and I won't go over that again, but clearly both chemotherapy and staging data we need to improve. The outpatient coding—Christine may want to say more about that—I think we can improve that too.

In terms of overall looking at quality, do we only look at survival? No, we certainly don't. One of the other major areas that we are measuring is what patients think of their care, the patient experience of care. Very shortly, we will be publishing a very large-scale survey of cancer patients. We sent questionnaires to just over 100,000 cancer patients who were in hospital in the first three months of 2010. We've got responses

back from 70,000 of them, or very nearly 70,000 of them; we are just preparing our report on that, but I think that will also help to show variations across the country in whether patients have access to a clinical nurse specialist, whether they have enough information, whether they understand what's wrong with them, whether they have confidence and trust in their doctors and nurses. I hope that will be a very valuable resource, because we will also publish it at team level, so that people can really see what they need to do.

Q34 Stephen Barclay: How do you know that the money is being spent effectively? There was a discrepancy of £1.2 billion between the figure you were putting forward and the figure that the NAO, which suggests that £1.2 billion wasn't being measured, but if we look at figure 19, there's a massive variance in the average number of treatment sessions by linear accelerator machine. What's unclear about that is whether you could be driving efficiency more by having some sort of tariff in order to get the least efficient actually driving down those costs, but I think the figures range from less than 2,000 up to almost 12,000 and, again, I just cannot understand why there is such a discrepancy in that sort of usage.

Professor Sir Mike Richards: I think there are three points you've made there; can I take them one at a time?

Stephen Barclay: Sure.

Professor Sir Mike Richards: First of all, there was the point about what we spend on cancer, what the programme budgeting shows and what the NAO report shows. Programme budgeting shows what is spent on cancer patients once they are diagnosed, and by the coding of the fact that they have cancer, we are then able to see what activity is going on, how many admissions they've got etc, and that's the source of the information that gives the £5.1 billion. The NAO very reasonably looked at all the other expenditure that there is on cancer that you can't pin on an individual patient, if you like, because they haven't got a diagnosis of cancer yet.

Q35 Stephen Barclay: But the screening has to be relevant because we've talked earlier about early diagnosis, so surely you're measuring that?

Professor Sir Mike Richards: Screening is incredibly relevant and we measure it. What they have done is to add in the cost of screening, which is perfectly fair but we've never claimed with programme budgeting that that says it's all about cancer. That is what can be ascribed to cancer through the coding process. So I would argue that both figures are right. The NAO figure is the more comprehensive figure for what we actually spend on cancer in this country, and I welcome that finding. So, that was your first point. The second point was about linear accelerators: I do just need to correct you on the figure. I think you're reading the figures from the left-hand side going up from two to 12.

Stephen Barclay: Yes.

Professor Sir Mike Richards: That's actually the number of machines within an individual centre. So the smallest of our centres—and I think there are

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about eight of them—have only two machines, whereas we have one centre, which, I suspect, is the Christie Hospital in Manchester, that has 12 machines. So it's the pale green line that shows the variation in usage, which is from about—

Q36 Stephen Barclay: Four to 10.

Professor Sir Mike Richards: Four to 10, if you take the extremes.

Q37 Stephen Barclay: So a massive variant.

Professor Sir Mike Richards: It is still a variation—80% of our radiotherapy centres are between 6,000 and 8,000. Now, we need to look at that. I can tell you if you look at the bottom end, at the ones that look as if they're least productive, I did look at which ones they were and two of them are in rural areas—one is in North Cumbria.

Q38 Stephen Barclay: Yes, but your '07 report was saying that the machines must deliver at least 8,000. That was in '07 and we're still not there.

Professor Sir Mike Richards: Yes, but if you take the machine in North Cumbria, we need two machines to make that a viable centre. It may not have the need in the local population for a full two machines, but you can't have 1.8 machines; it's impossible to do that. So, I would argue that for the people of North Cumbria, it's very valuable for them to have a centre that's there, because if not they would either have to travel to Newcastle or they would have to travel down to Preston. So it is a very valuable resource. One of the other centres that is low on productivity is Taunton, and Taunton has only just opened up as a centre. I am quite sure that over time the productivity of that centre will increase. So I think we need to learn from this. There are explanations sometimes for these variations.

Q39 Chair: Sir Mike, you said that Christine Connelly might want to comment on this issue of coding with patients and indeed I would like her to. If you look at paragraph 3.13, it says that “up to £240 million could be saved between 2008 and 2018 if improvements in survivorship follow-up were made”. But the subsequent paragraph says, “It was not possible to measure progress against this aim as insufficient information is available to understand the reason for an outpatient appointment (whether it is during treatment or for monitoring purposes) or whether the patient has cancer, with around 97% of outpatient data in HES not coded for a disease diagnosis.” Christine Connelly, you're the Chief Information Officer, what are you planning to do about this?

Christine Connelly: The first thing that we need to do is to ensure that the hospitals understand why they need to provide this coding and that there is some utility back into the hospital itself in terms of providing that information. So a lot of work that we are looking at around the consultation that's out on the Information Revolution is about saying how do we make it clear to people that information itself is valuable inside the system and then how you manipulate it comes after that. It's essential for us that

we improve the structure of the data that we collect and then the coding of the data that we collect to allow us to draw more insight from that data in the longer term.

Q40 Chair: At the moment, if you've got data that the NAO is collecting, where your own National Clinical Director says, “I just don't believe the 3.5% figures,” it's not much use to anybody is it?

Christine Connelly: Well, I think when data is poor, the first thing that happens when you go out and collect data is you discover it to be poor, and you then know that it's poor and you can take some action and improve it. If you don't attempt to collect data in the first place then you can do nothing at all. So I think having a data set that we would absolutely say is not good enough is the first start of a journey and it's important for us to take that information, work on it and then improve it.

Q41 Ian Swales: Are you suggesting there is a resistance to providing data? That's what it sounded like from your opening remarks, that you're having to persuade people that providing data is actually useful.

Christine Connelly: I think that people across the NHS provide lots and lots of data and what is important is that the people who actually at the point of recording the data understand how it's going to be used and why that piece matters. If you understand that then you do a much better job of recording it. So it's not that anybody is particularly resistant, but we need to make people aware of what that information will be used for and how it impacts the quality of treatment of patients. In some places, they may think the information is being used only for payment purposes, rather than for patient treatment purposes, so to actually make those links in the mind of everybody involved in the whole chain of care is really important. So I wouldn't like to suggest that people are resistant to it, but with a million things going on every day, you are prioritising and making decisions.

Q42 Chair: How do you get assurance about the quality of data for cancer services generally?

Christine Connelly: The first thing to do is to collect data, publish it, be very transparent about it and then to start the debate on the data that exists. In all sets of data that we've collected over time, the first thing that happens when you make data available is that people start to question the data itself and that then leads to a good, rich conversation about how you improve it. Is it the way you've defined it? Is it the way you collect it? Is it an untrue comparison? So there are lots of levers when you look at a full data set that allow you to improve it and the first thing that we would say is to collect it and publish it, not to keep that locked away in a drawer, because when it's all locked away in a drawer and you have people thinking they know what they've got, you actually can't do very much with it.

Nick Smith: That's music to the ears of this Committee, Christine. We love data here. I've got a question about the new commissioning organisation within the NHS. How are you going to ensure that

new commissioners, particularly GP commissioning consortia—do you want to come back to that?

Chair: We'll deal with that very definitely. Can you hold that thought because we will definitely come on to the structure and how it's going to change and impact on things, and I'm sure Mr Flory will want to come in on that.

Q43 Stephen Barclay: Just really following on, is there an adequate urgency from the Department in terms of data, because what struck me in the report was some areas are able to get data on outcome measures to you within six months, but the norm seems to be 18 months, and it just seemed odd that some areas can do it in six months and other areas take 18 months.

Professor Sir Mike Richards: I think that's one for me, because it's cancer registries. The answer is if you go back five years we were probably taking three years to get those data, not 18 months, so there has been a major improvement. Eighteen months is on a par with what cancer registries round the rest of the world do, but one of our registries has actually demonstrated it can be done in six months. They have put a particular effort into that. I think they are to be commended on that and as a result of that we have also said to the other registries, "It's now time to catch up."

Q44 Chair: That's the one in the east of England?

Professor Sir Mike Richards: That's the one in the east of England.

Q45 Chair: It doesn't surprise me that it's the one in the east of England.

Professor Sir Mike Richards: I'm sure it doesn't, Chair.

Q46 Chair: It is nonetheless the case that the Cancer Plan was published 10 years ago. Now, I think taxpayers are entitled to assume that after 10 years of this we ought to have good information on all aspects of cancer services. Why don't we? Where are the biggest blocks, the inertia? Colleagues were talking about the desire of clinicians to help—as was Christine Connelly—if they don't think it's going to make a difference to patient care, but what are the biggest blockages and how will you unblock them?

Professor Sir Mike Richards: First of all, we have made very good progress on information and I would say that, by and large, the information system available for cancer in this country is on a par with other countries. I want it to be the best on cancer information; I want to be the best on cancer information because I think it will drive quality and so that is my own goal for cancer in this country.

In terms of what the barriers are, the blockages are, there are a number. First of all, we do have to convince, in some cases, clinicians, of the need to collect these data, the staging data. As a clinician I can say that since 1982 I was able to collect and record information on the stage of all the patients I looked after, because I worked in units that were doing that. We had comprehensive data on staging of all our patients, so it can be done, is my point.

Q47 Chair: Can I just clarify this staging point, because it's very important. Figure 6 goes into this and you mentioned the east of England. What figure 6 is saying—correct me if I'm wrong—is that in 70% of cases in the east of England they collect and have the information on the stage that the cancer had reached when it presented to the NHS and in 30% they don't, whereas in the North West, the one at the top, in only 15% of cases did they actually have the information on what stage the cancer has reached when it presented and in 85% they don't. In either of those cases it could be that it was very early or it could be middle or it could be late, but in the 30% and in the 85% of cases they don't know. Is that correct?

Professor Sir Mike Richards: Yes, the registry doesn't know. Now, in some of those cases, of course, the clinician will have known but not have recorded it at the time that the multidisciplinary team was meeting. One of the things we need to do is to get multidisciplinary teams to make recording of that data absolutely routine.

Q48 Chair: The Cancer Campaigning Group believe that GPs should be incentivised to diagnose patients at an earlier stage. How will you do that?

Professor Sir Mike Richards: That's the incentivising them to refer the patient earlier. That's a slightly different point from recording the stage. I will welcome that as well; I think we do need to. The difficulty has been, from answering that specific question, getting incentivisation at the individual practice level, because the number of patients that an individual GP has with cancer in any one year is really quite small, and so just depending on the mix of cancers—some could be early, some could be advanced—it would not be fair to base points for the Quality and Outcomes Framework on stage. Now, if you take the size of a PCT or in the future the size of a GP consortium, I think that's quite a different matter and I think we could potentially incentivise at that level.

Q49 Chris Heaton-Harris: Mr Smith quite rightly pointed out that this Committee is never happier than when it's bathing in a kind of warm bath of data.

Stephen Barclay: Usually, it's so lacking that the bath is empty.

Chris Heaton-Harris: But I'm just wondering—and we're kind of fixated on this for all the right reasons—but whilst you're looking at the data, which you've just mentioned it in passing in a previous answer, where does that data transfer itself into what the Department of Health does in trying to drive outcomes? It's okay collecting all this stuff; how does the next stage come? Because we're still at the stage where, with prostate cancer, you're five times more likely to die in some parts of the country than in others. I think it's South East Cambridgeshire where only 12 men die per 10,000 cases; in Tottenham, it's 57 men per 10,000, and there's these disparities across the whole country in different cancers. Data's fantastic, but if you're not learning from it and using it properly, it's pointless.

Professor Sir Mike Richards: I would argue that is why we've called the National Cancer Intelligence

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Network an intelligence network, not just a data network. We want to make sure that the data we generate are first of all turned into intelligence and from that into action and that is why we have also made sure that we have expert groups relating to each different cancer—breast cancer, colorectal cancer, lung cancer—working with us in the National Cancer Intelligence Network, so that we do make best use of the data. So part of that will be going back to things like the GPs who are not using the two-week wait as much as they might, feeding that information back. That is a very powerful lever for them, saying, “Right, I will do something about that.” Equally, if we have data that says that one hospital is better than another, I can tell you as a clinician, no clinician likes being the bottom half of any league table. It’s a very, very strong stimulus to get better.

So we are working very hard to make sure the data don’t just come into me and my team, but that we also get them back out again. That’s why last year in the second annual report on the Cancer Reform Strategy we provided data about a whole range of different things to do with cancer at the individual PCT level, so that the PCTs, as commissioners for cancer, could see what their picture was, whether it was on one-year survival rates, on screening rates, on emergency admission rates, all of those things, in order to get that back to PCTs. We have created something called the Cancer Commissioning Toolkit, which is there for commissioners to use—it’s not only commissioners actually, the providers can use it as well—so that they can see what their performance is and they can benchmark themselves against others.

Q50 Chris Heaton-Harris: What about the public and receiving these data?

Professor Sir Mike Richards: I think we can do more on that and I think we should, and I think that is entirely in line with the Government’s commitment to information and choice. I think we should be finding ways in which we can put the information about different hospitals, different PCTs into the public domain in a way that the public will find useful.

Q51 Chair: Can I move on to PCTs and expenditure, because you talked a minute ago about information for PCTs? One of the most striking aspects of this report is the variation in expenditure on cancer services. In paragraph 2.5, it says that it varies: “Reported PCT expenditure... varied from £55 to £154 per head of the population,” and if you look at paragraph 3.3 on page 31 it says that “23% of the variation is explained by the number of patients,” or the extent of activity or the local staff pay and other market variations; 20% is because of the needs-based formula and 3% because of the size of the PCT, but that still leaves 54%, more than half, unaccounted for. In other words, you can’t explain why there is this variation. Now, what are you doing about that?

Professor Sir Mike Richards: Well, the first thing, again, is to understand that there is this variation. I welcome the work that the NAO did on this; I also welcome the work that we have done with the King’s Fund on this which came to very, very similar conclusions that there are unexplained variations

between PCTs in the money they appear to spend on cancer. Now, there are two things that that could be down to. It could be real variations between PCTs, in which case there’s certainly scope for efficiency, and it could be that we haven’t got the measurement of expenditure right. It’s probably a combination of those.

Q52 Chair: A bit of both. The truth is—isn’t it?—that the commissioners haven’t really taken value for money that seriously. It says in paragraph 13 of the report, this is page 7, that “despite being a focus of the Strategy, only around half of the PCTs had identified where expenditure which does not benefit patients could be eliminated and just 20% had achieved quantified efficiency gains as a result of implementing the Strategy.” Why haven’t they put more focus on value for money?

Professor Sir Mike Richards: I think it would be entirely unfair to say they haven’t put emphasis on value for money generally, but as to whether they have done that with a cancer spotlight or cancer focus, I think the answer is this survey tells us they haven’t, because this is what the PCTs themselves said. So I can’t dispute that and I wouldn’t dispute it. I think what they have been doing is focusing on more generic issues, such as emergency admissions for whatever cause, not just for cancer, but cancer, heart disease, chronic obstructive pulmonary disease, diabetes, the lot.

Q53 Chair: And only one-third of these—this is paragraph 2.4—“had done so for cancers as a whole”.

Professor Sir Mike Richards: Yes, I agree. I would like them to focus more on cancer.

Q54 Chair: This is quite extraordinary in a way, because I mean famously when the Government first focused on this and you were appointed, the two big headline items were cancer and coronary, and then the third one came along, which was—not dementia, that was the fourth—

Professor Sir Mike Richards: Mental health.

Q55 Chair: Mental health. Diabetes, I think, actually was the third one. By focusing on those two, it allowed the PCTs to take their eye off some of the others. But cancer’s been right at the top of the agenda for the centre for a very long time now and yet only one-third of PCTs had assessed the strategy for cancers as a whole.

Professor Sir Mike Richards: Assessed it from a financial angle, yes. I completely acknowledge that they could do more, and I think if they did do more there are areas in which they could make savings and at the same time improve the quality of care. That’s something that clearly, over the next few years, given the financial constraints on the NHS and on the country as a whole, we have got to do. One of the things we have pointed them towards is measuring bed days because, as I’ve already said, we measure that very well, very quickly, that’s good and if they focused on that, because inpatient admissions are such a large proportion of the cancer spend, if they focused on that alone, we would make a lot of efficiencies.

Q56 Stephen Barclay: What concerns me, Sir Mike, is the penny still hasn't dropped with some of the PCTs. You said earlier in your evidence we have to get a tighter grip on the data. If we look at paragraph 2.11, it says—and this follows up Richard Bacon's point—"Just 22% of PCTs had assessed the value for money delivered by their cancer service providers... 12% had no plans to carry out such an assessment." So for 12% they're not even intending to carry out any assessment. Does that surprise you?

Professor Sir Mike Richards: It does indeed. When this survey came through, I was surprised by the finding. I go back to saying it does not mean that PCTs aren't interested in value for money. I can't believe that there is a PCT in the country that isn't interested in value for money. I just don't think they're focusing on cancer as an area for that and I would encourage them to do so.

Q57 Stephen Barclay: Why do you think PCTs lack confidence, as the report says?

Professor Sir Mike Richards: I think that's confidence in having all the data, and remember we spoke earlier about the fact that the chemotherapy data are not as good as they should be. It's only very recently that we've had radiotherapy data that are of high quality, and so as those make up a significant chunk of cancer spend, I think until now it's fair to say they haven't had confidence in the totality of cancer expenditure. They can have confidence on the expenditure related to inpatient care, which is half of all the expenditure.

Q58 Stephen Barclay: But I thought the world-class commissioning programme, which the Department launched in December 2007, said its programme was to improve PCTs competence and ensure excellent financial skills. In terms of financial skills, the actual number of PCTs rated red increased and this report is saying they lack the confidence and are not proactively monitoring value for money, so has something gone wrong with that world-class commissioning programme or are there things from that programme that are still not being delivered?

Professor Sir Mike Richards: I recommend that one to Mr Flory.

David Flory: Thank you, Sir Mike. The evidence of the performance of Primary Care Trusts in recent years and in the period since the world-class commissioning initiative was introduced has been one of incremental improvement in commissioning. The analysis that we see year on year and most recently some months ago, where the Primary Care Trusts reported their own latest assessment, and across many of the dimensions of world-class commissioning shows improvements in their performance as commissioners. Indeed, if we look at the Audit Commission's assessment of the financial management undertaken by Primary Care Trusts, one part of which is the pursuit of better value for money, then you would see over the last three years a significant improvement in what's referred to as the ALEs scores, the Auditors' Local Evaluation of PCTs. So there's strong, independent, audited evidence that the financial management in Primary Care Trusts,

which is only one part, but a very important part of their overall commissioning responsibilities, has significantly improved in the score and ratings that we see in there.

Q59 Stephen Barclay: Well, look, between 2008 and 2009, the number rated red increased from 8.6% to 8.9%, so it was going the wrong way. As this report is saying, 66% have still not carried out an assessment and 12 have no plans. So if it's incremental, when are we going to have a date by which the remaining 12% have done it? What's concerning me with all these gaps in data—and we'll come on to the point Nick Smith raised in due course with the GP consortium—is who is responsible for addressing these gaps in data and what sort of timelines are going to be attached. Because there were a number of recommendations in the 2007 report, but no dates attached to them. So what's unclear is, if it's incremental, when are we going to have all the PCTs covered? Do we have a date in mind for that and who is actually the owner of ensuring that happens?

David Flory: Well, I think that the "when will PCTs get to a point of improvement" is a discussion that in some ways is now taken over by the White Paper and the reforms to the system that are about to be introduced.

Q60 Stephen Barclay: So nothing before 2014 then, with the GP Consortium.

David Flory: Well, I think that on that GP consortia are now beginning to set themselves up; they're operating in shadow form. The Department will soon be announcing pathfinder consortia, but they're not going to wait around until the PCTs have gone in 2013 before taking on their commissioning roles and responsibilities, so I feel more optimistic about the progression in continuing to improve commissioning arrangements in the short term.

Q61 Stephen Barclay: So would you expect those 12 to have addressed it then before they're disbanded?

David Flory: Yes, I think that having looked carefully at the wording in paragraph 2.11, and picking up the point that Sir Mike made in answer to your previous question, I do think there's an element in this, in the responses that PCTs have given to this, of different interpretations of what the question means.

That's easy to say, but if I could go on to illustrate: the ways in which the system organises itself to improve productivity, efficiency, value for money is a big part of what the Department sets out through the Strategic Health Authorities for the NHS to respond to year on year. Each year, when the tariff prices are set for those services that are part of the payment by results system, there's an inherent efficiency requirement that's set for providers of NHS services to respond to, which is reflected in the resetting of the prices from year to year. So providers simply have to drive that sort of efficiency in their operational service delivery in order to be able to contain cost within tariff price. So some of the issues that the Committee referred to earlier around productivity of linear accelerator machines, about the way in which the services are organised in the hospital, like all services, they're going to have to

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deliver those sorts of year-on-year efficiency gains; that's an inherent part of the system and the way it works.

Of course, for the commissioner that's slightly different. The commissioner pays the tariff price to the provider and that in-hospital operational efficiency is down to the provider. What the commissioner, of course, is responsible for in driving better value through the money in which it's allocated, is getting the right pattern and range of services, in thinking more about the whole pathway of care for patients through primary care, through diagnostic phases where necessary and into hospital care, and it's in those areas that the commissioners of service need to review their overall priorities; that they are setting the investments in those priorities with a view to driving out better value for money for the taxpayer, if you like, across the whole spectrum of services they commission. I think that's what paragraph 2.11 highlights; that's where the commissioners tend to focus, rather than on the service-specific value for money.

Q62 Chair: Sir Mike, I'd like to pursue this issue of how the whole programme has been managed, because there's been a lot of extra money; everyone knows that. Paragraph 3.2 says that the "NHS Programme Budgeting data indicate..." an increase from £3.4 billion to £5.1 billion, but the NAO's work suggests that it's £1.2 billion more than that; it's £6.3 billion, which raises the question: to what extent has this been run as a programme, with the disciplines that running it as a programme would entail?

Professor Sir Mike Richards: It is a programme; it's not a programme for which I hold the £6.3 billion budget.

Q63 Chair: You're a bloke—a very fine bloke—with a desk in Richmond House and a telephone, basically, is what you're saying.

Professor Sir Mike Richards: I hope rather more than that, but we have a devolved NHS where we give responsibility PCTs, at the moment, for commissioning, and to trusts for delivering. I act by influence and not by having the budgetary authority. In other words, the Department of Health doesn't give me the £6 billion to spend and then allocate it, but I can help to drive the NHS in the direction that will improve quality through a number of different levers that we have, including having a plan, setting out what that plan is, what the direction of travel should be, working with the networks, through the networks to the PCTs and the trusts, and it is a role of influence, not of direct authority. I get my authority from the fact that I have been fortunate to have political support across the political divide over the 11 years I've been working in this job and because I've had support from the top of the Department of Health throughout that time.

Chair: I want to come on to the NHS Reforms in just a moment, but before I do, can I bring in Austin Mitchell; he's been waiting patiently.

Q64 Austin Mitchell: Can I just shift the emphasis slightly sideways or perhaps downwards, because it's

suggested from time to time that there's a discrimination in favour of women because of this massive concentration on breast cancer and against men because of inadequate concentration on prostate cancer. I've had a letter from Professor David Neal of the Department of Oncology at the University of Cambridge, and it's written that there's a suggestion of his patient, Mr Glen Smith—good on you Glen Smith, I say—and it says that again, it's a question of early diagnosis of prostate cancer, but the levels of life saving would vary somewhere between one life saved for between 15 and 40 men who are diagnosed with prostate cancer if there was a test. It doesn't recommend a universal streaming test; the prostate-specific antigen test reveals all kinds of things that are not necessarily fatal or dangerous, but it does say that men should be able to undergo a PSA test by their general practitioner, but that many of them can't because the general practitioner refuses, won't do it, because the men don't know about the test and all sorts of other reasons. Now, what's your view, first of all on the usefulness of this test and, secondly, on whether men should be able to go along to their doctor and demand the test as a means of early diagnosis.

Professor Sir Mike Richards: First of all, I genuinely do not believe we are biased in favour of women and against men. Let me make that very clear.

Q65 Austin Mitchell: No, my wife wouldn't allow me to say that either, but I just raised it because it's raised a lot of times.

Professor Sir Mike Richards: The reason we have, for example, a screening programme for women, is that we have very good evidence of the benefits of that screening programme, both from the randomised trials and from the evaluations that we've done on the programme since.

Q66 Chair: Can I just stop you there? It's not in dispute that there's less evidence; in fact Professor Neal's letter, which I think you've seen, says very clearly, "I do not think the evidence is strong enough to recommend a Department of Health-led screening programme"—which you're nodding at—"but I do believe that the evidence now demonstrates that early detection will save some lives and therefore men should know about it and should be able to access the PSA test." Now, first of all do you agree with that?

Professor Sir Mike Richards: I work very closely with David Neal. I do agree with his assessment of the situation. There's a question of what is the right line from here. Let me try to explain. First of all, I think everybody acknowledges that the PSA test is not a very good test because it can miss some cancers even when they're there, but it can also, if it's raised, lead to really very large-scale over-diagnosis.

Q67 Austin Mitchell: Is it the only test?

Professor Sir Mike Richards: It's a blood test, the PSA test.

Q68 Austin Mitchell: Is it the only test available?

Professor Sir Mike Richards: Sorry—is it the only test? At the moment, yes it is. All the scientists are working to try to develop better tests, but at the

moment it's the only test we have. The problem is that if you go to the best trial that there is that has looked at PSA screening, it did show a reduction in mortality. That's a good thing. But at the same time, for every one life saved, they reckoned that 48 men would be over-diagnosed with cancer. Now that's a balance. It's a balance that some men may wish to take, but what's very difficult is to tell which cancers are going to be of no problem to the man during his lifetime and which cancers are going to be lethal. There are studies that have been done from post-mortems of men at the age of 80 that suggest that 80% of men at that age have prostate cancer. It's not that 80% of men die from prostate cancer; you can live with it there. So there is this major risk of over-diagnosis.

Now, obviously I believe this is a matter of informed choice, which gets back to your original question. Yes, I do think that we need to make men aware of this, but we also need to make them aware of the downsides of having a test and then potentially being diagnosed and, if they go on to treatment, it could make them incontinent, it could make them impotent, and all of those downsides to it, and then they can make their own minds up. What we have said very clearly since 2001 is that, subject to men being given the information on the pros and cons, men should have access to a PSA test.

Q69 Austin Mitchell: And the doctors should do it?
Professor Sir Mike Richards: Yes.

Q70 Austin Mitchell: Because David Neal says they don't—or a proportion of them.

Professor Sir Mike Richards: I think David Neal is right about that. We have had something called the Prostate Cancer Risk Management Programme, and since 2001 our advice to GPs has been that, if a man wants this test and has been informed of the pros and cons, then they should have access to that test.

Q71 Chair: Thank you very much. Before we move on to the NHS Reforms, which I really do want to get on to quickly, I just wanted to bring in the National Audit Office on the question of the census.

Karen Taylor: Yes, I just wanted to explain we don't actually accept that the differences in the responses were differences due to interpretation. We went to a lot of trouble to make sure that the questions were very unambiguous, were black and white. We designed the questionnaire with input from the Department; we piloted it; we went out to PCTs and filled it in with them to understand how they would interpret the questions. The questions were yes or nos; they weren't shades of grey in many instances, particularly where we were asking about the value for money and whether they'd identified things that they should stop doing that the Strategy says that they should do. So we said, "The Strategy says you should identify things to stop doing because they don't add value; have you done so, yes or no?" So they were very black and white.

As I say, we piloted it; cleared all the questions with the Department, went through the Department's own process of approving questionnaires, which is called the ROCR process—Review of Central Returns—and

we only asked questions that we felt we needed to ask because we couldn't get the information from any other source. In doing the survey, we told the people completing the survey that the results would be shared with the Department and would be shared with people like the Health Care Commission, so that maximum use could be made of the results. We also asked the Chief Executive, as the accountable officer for the Primary Care Trust, to sign it off. So we think we went as far as we could in trying to make sure that the answers we got were as valid as they could be.

Q72 Chair: Professor Richards, did you want to comment on that?

Professor Sir Mike Richards: That wasn't my earlier comment. I don't know if Mr Flory wants to comment on that. I accept these results as they are on the page.

Q73 Chair: Mr Flory?

David Flory: Very clearly, as the National Audit Office colleagues say, I was surprised by the conclusion that was drawn in paragraph 2.11 and was being speculative about the extent to which there might have been inconsistency in the way that it was responded to.

Karen Taylor: We have published it separately—the whole questionnaire and the responses separately on the website—for you to read fully what was asked and what was said.

David Flory: I think the most important thing in this is it's not a question of saying the responses can't be right and therefore there aren't issues for us to take forward. Clearly, there are issues in the way that Sir Mike has described. But with Primary Care Trusts, in our holding them to our account for how they do their business, we need to take that forward from here.

Q74 Stephen Barclay: And what are the practical steps there in doing that?

David Flory: We go into a cycle with the Primary Care Trusts, which effectively, to over-simplify it a little bit, is that the Government sets out its priorities, its requirements, for the National Health Service for the forthcoming period. We translate that into an operating framework that spells out in some detail absolutely the issues that all NHS organisations need to address in their forthcoming planning and investment plans. The Primary Care Trusts produce their plans in response to those priorities; how they're going to get to grips with the issues that everybody needs to get to grips with, as spelt out in the operating framework, and the choices they are then making about their local priorities that go alongside those. Those plans are then assessed by Strategic Health Authorities in the system, as is now, and challenged and tested for their appropriateness, and then the Department of Health signs off—having gone through a process of challenge—the Strategic Health Authority. So there's a very ordered and structured systems on which plans are approved and then organisations are held to account to do what they have said they are going to do in all areas of their business. We have many examples where issues that come out from reports from National Audit Office and other

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places inform the way in which those priorities and detailed requirements for plans are set.

Q75 Chair: Mr Flory, I'd like to move on to the White Paper and the impact of this on the Cancer Strategy. Paragraph 24 sets out how the Secretary of State in July asked Sir Mike for a review of the Strategy to determine if it's right for delivering improved cancer survival rates and it goes on to say the NAO finds "that there is a risk to the successful delivery of any future strategy unless there is considerable further improvement in the information used to support its implementation. As part of its review of the Strategy, the Department should develop an action plan which identifies the roles, responsibilities and timelines for taking," a series of actions there which are to do with common standards, the speed of publishing data, diagnosis, rationalisation of information, variations in productivity and so on. Now all that's going to happen—if it happens and you accept this recommendation, and you've signed this report I take it—against a background of considerable change in the NHS. So what drivers will there be in the refresh of the Reform Strategy which will deliver improved survival rates?

Professor Sir Mike Richards: Obviously, I can't preempt the content of the new Strategy. We have committed to publishing the Strategy in winter 2010, so it's not that far off, but it won't surprise you to hear that what we're doing is to align cancer with the direction set in the White Paper. So there are several major drivers, the first of which is information. I think I can say there will be a major emphasis in the new Strategy on better use of information; a lot of the points that are being made here. We will also be shifting the emphasis from process targets to outcome measures; very much a White Paper commitment. We will also be making sure that the new commissioning arrangements work as effectively as we possibly can to drive cancer changes. Then the final bit is about the separation of public health from the NHS, and there are certain clear things that the public health service will need to do: reducing the incidence of cancer through prevention measures, screening, raising the awareness of symptoms and signs with the public. That will all rest with Public Health England, and then on the other side there are the actions that the NHS will need to take to improve outcomes. So all of that will be spelt out in greater detail in the new Strategy.

Q76 Chair: What is future of the 28 cancer networks and how will they relate to the new GP consortia?

Professor Sir Mike Richards: Well, again, I can't preempt what the strategy is going to say in that regard. But what I can say is that networks, I believe, have a very useful function in supporting commissioning. They can provide the advice, as they currently do to PCTs, to GP consortia. Now GP consortia will be free to choose to get advice from wherever they wish, but they might well want to turn to networks to get that advice.

Q77 Ian Swales: Given this new GP consortia system, are you worried about, if you like, a disincentive to push for early referrals and the things

that you know lead to better outcomes, and are you concerned about actually data getting worse in the new situation rather than better?

Professor Sir Mike Richards: I sincerely hope there is no risk of data getting worse; I am absolutely convinced we have the levers in place to make data better and I'm sure we will continue to do that. I think what we will need to do is to engage with the new consortia in exactly the same way as we currently engage with PCTs, often through networks. I think GP consortia will see the need to improve survival rates and it will get a new focus on to that particular topic.

Christine Connelly: Perhaps I could come in on how we see the improvement in data in the new system? So the first thing to say is that in the White Paper it's very clear that the setting of standards for data in the health service will sit with the NHS Commissioning Board, so there's an expectation that that single point of accountability will define the standard and then it will be a requirement for providers in the system to surface data to that standard, which should make things move faster than they have previously and with some clarity on who has got to do what by when in terms of providing data to that standard.

When a provider surfaces that data, there are a number of different things it can then be used for. Obviously, an individual patient's information could flow back to the patient, would flow from an acute trust to the GP, so you would expect that to happen. But also we would then be in a situation where we're able to collect the data and the White Paper and then the subsequent consultation on the Information Revolution is clear that we would expect to collect the data in an aggregate form once through the information centre, which would then give us a clear point where we would say, "This is the source of aggregated data coming out of individual trusts." Then the information centre would be expected to publish that data and allow other third parties to come in and pick it up and present it to different groups in ways that may be more meaningful for them, to perhaps mine that data, to get different insights from different perspectives.

So we would expect to see much more published, much more in the public domain, the source of it coming out of the health service, but various interpretations that would help people, patients particularly, to exercise their choice in an informed way and help people to then ask more questions of the system as a whole. We would also expect that aggregate data to be used by commissioners to take a view of their population as a whole to help define and design services that would make sense for that particular population, and we would expect cancer services to be part of that. But in terms of the broad perspective of the new system and how it would work in surfacing and improving data quality, that's part of the plan.

Q78 Ian Swales: It sounds fantastic; I've been here since May; I think that's the best description I've ever heard of a new approach to data that makes us feel good. I guess the only supplementary to that is data quality right at the bottom end. So you're seeing a key part of the commissioning process as specifying that

data must be submitted, must be high quality and so on, I suppose you could argue the decommissioning process if consortia or rogue elements in the system appear to not be toeing the line then that becomes part of a serious conversation.

Christine Connelly: Yes. We would expect it to be a responsibility of different parts of the system to do particular things with data. In terms of attacking the quality issue the consultation document talks about data being captured in the moment, so in the middle of when a patient is having a consultation with the clinician. To capture the data then would provide, we believe, far higher quality data than capturing it after the fact. Now, there are many issues associated with that and we expect to get some responses on our consultation to say how far can we go with that and how realistic is it to push it, but to actually get better quality data you have to capture it there and then if that's at all possible.

Professor Sir Mike Richards: Can I give you a practical example on that, which is the one about chemotherapy that we were talking about earlier. If we can capture the data at source, which is when we've got the chemotherapy data set when patients are being prescribed the chemotherapy, it will go into an electronic system that will have value to the clinician and therefore to the patient. They will be able to see exactly what the patient has had before when they're prescribing the next course of chemotherapy, and we will then be able to extract information from that in order to see what the patterns of chemotherapy are across the country and whether there really is variation. So that will be capturing it at the time, which at the moment we don't. The chemotherapy coders later on put the code in and that is where sometimes some hospitals, frankly, do it better than others. But if we capture it at the source, it will have value all round.

Q79 Nick Smith: Sir Mike, earlier on you sort of described yourself as an influencer, albeit with the weight of Whitehall and political support behind you. And Christine has given a detailed idea of the sort of new world we're going into, with the new commissioning arrangements. Can we just test out this idea though of commissioning boards making these requirements of the new consortia? I'm interested in how the new consortia will either be enforced or incentivised to use the data intelligently and to provide the services—the value for money services that we've talked about—because it still feels a bit academic to me. I'm just not sure that the earlier weight you've enjoyed, Sir Mike, will be seen through with the new commissioning consortia and we'll get the same weight of change in the future given the new arrangements.

Professor Sir Mike Richards: I actually don't see any reason why I should have less influence with GP consortia than I would with PCTs, to be quite honest. I would hope it would be similar or greater. I think the more that we can provide them with high-quality data that they can act on, then I think whoever is doing the commissioning will respond to that. So I think our task is to get them meaningful information across all

aspects of cancer. I think we're there on some parts of it now; we're not there on others.

Q80 Stephen Barclay: Could I just pick up in terms of the transition period, because there's a concern what will happen with the PCTs and particularly them losing staff over the period before the GP consortia become fully functional? In the paper you're bringing forward in the winter, will you have timelines attached to closing some of these gaps on data quality?

Professor Sir Mike Richards: Again, of course, I cannot commit to what's going to be in the Strategy. What I think I probably can say is that obviously there are two phases of this transition. There's the phase from now until the end of this coming financial year, 2011–12, where things remain the responsibility of the Department of Health, and then from April 2012 onwards things are under the responsibility of the commissioning board. Now, one thing that is very clear is that we should not at this stage be tying the hands of the commissioning board because the whole point is to set the commissioning board free. What we are doing within this next year is to try to improve a lot of the data collection, so that it is fit for purpose when the commissioning board comes into play.

Q81 Stephen Barclay: So, to take a specific to bring it to light, the 97% figure for what isn't coded at the moment—what will that be in 24 months time? Are you working to a target? Are you measuring it in that way? Or is it more general than that?

Professor Sir Mike Richards: I think I'll stick to the ones that are specifically cancer. We will over a relatively short period be setting ourselves goals in terms of collecting better data on staging, on what gets to cancer registries, on chemotherapy, on publishing data, on radiotherapy, those sorts of things. Those are cancer-only things, if you like.

In terms of the outpatient diagnosis, it's in some ways not as much a problem for cancer as it is for some other areas, because if a patient has had a cancer diagnosis and then comes back—let's say they've had a bowel cancer—they come back to the general surgical clinic. I will make the reasonable guess that that is actually related to that cancer. Equally, if they come to an oncology clinic, I will also make the reasonable assumption that that is a cancer-related attendance. If they go to a completely different sort of clinic, like a rheumatology clinic or a diabetic clinic that's probably something different.

So there are things that we can do because we can link these data sets. We know about when they had the cancer; we know what speciality they are attending; we can to a certain extent predict what attendances are for. I think there is a different issue, though, about overall we improve diagnostic coding. I don't know if you want to say anything about that for outpatients.

Q82 Chair: So in two years' time that figure's probably going to be the same? You're relaxed about where that's going to go?

Professor Sir Mike Richards: I'm relaxed because I believe we can get to that data—

Chair: Through other sources.

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Professor Sir Mike Richards: From other directions or other sources. From a cancer point of view, I've got my solutions.

Q83 Joseph Johnson: When we move to a world of GP-led commissioning, how easy it is going to be to replicate the economies of scale that the PCTs have in commissioning what is, as the NAO report says, a very complex set of medical services. How are GP-led consortia going to get the same economies of scale?

Professor Sir Mike Richards: In the same way as for a lot of things to do with cancer, we need PCTs working together, because services need to be provided for populations of one and a half or two million people. I would expect GP consortia to work together. Now GP consortia will be of different sizes, but certainly from a cancer point of view, I think it will be very clear to all of them that they will need to work in federations—

Q84 Joseph Johnson: Federations of consortia?

Professor Sir Mike Richards: Of consortia, yes.

Q85 Joseph Johnson: So how many consortia, first of all, do you expect, and then how many federations of consortia to you expect and will they basically be PCTs?

Professor Sir Mike Richards: In terms of the numbers of consortia, I think you're probably more up to speed with that than I am.

David Flory: GPs in their practices are still working through what their preferred consortia model will be locally, so if I was to speculate at this stage, I would say somewhere up to 300 consortia.

Q86 Joseph Johnson: Three hundred consortia, and then in order to replicate the economies of scale for PCTs—how many PCTs are there? Around 120 or so?

David Flory: There are 152 PCTs. But of course what we need to remember is that the new commissioning board will itself commission services and will itself commission the more specialist services. So what we will see I think is a situation whereby a commissioning board clearly will set standards; it will define improvements in terms of the outcomes for patients, and all of those things will be reflected in the way in which it holds GP consortia to account. It will, of course, commission some services itself, as I've just described, and what will emerge, I think, based on the advice that the cancer networks give, is we will see groupings of consortia come together and either ask the commissioning board to commission more than the very specialist services on their behalf in a particular area, or indeed to organise themselves to do it collectively, supported by the advice that the networks and others will be able to provide. So I see a mix of operation models.

Q87 Joseph Johnson: But do you feel confident that you'll be able to replicate the economies of scale that the PCT structure can currently achieve?

David Flory: Yes, I do, because I think that the commissioning board's roles and responsibilities are central to this. It will need to ensure and hold

consortia to account for its effective commissioning, based on lots of the things this Committee's discussed.

Q88 Chair: Sorry, go on. I'm sorry; I wanted to ask a question, but you hadn't finished your sentence.

David Flory: I almost had, Chair. It was simply to say I was confident, on the basis that the role the commissioning board would play in holding consortia to account, that consortia won't simply be left to do it as they wish.

Q89 Chair: Nonetheless, what you've just describe is quite fluid. In addition to the economies of scale, there's the issue of the quality and consistency of the data. Now it says in the report that "Commissioners"—that's the present commissioners—"do not link cost and activity data to incidence, prevalence and survival data." Will moving to GP commissioning make that easier or more difficult?

Professor Sir Mike Richards: One think I can say about that is that through the National Cancer Intelligence Network we are already starting work on saying the information we currently provide at PCT level, can we now cut that in a different way; can we build it up from General Practice level so that we will be able to give it at consortium level? So as soon as we know what the final configuration of the consortia is, we will be able to give comparable information by consortium that at the moment we currently give to PCTs.

Q90 Chair: Is there any thought that one might align the cancer networks with the consortia for cancer services?

Professor Sir Mike Richards: If you look at what the geographical shape of cancer networks currently is, they basically reflect patient flows—flows from the community, to primary care, to secondary care, to tertiary care—and so they're mostly described by the catchment population of a tertiary centre. I don't see that changing and I would see therefore that the consortia who share those flows into a tertiary centre will want to work together to get the best out of the tertiary centre.

Q91 Austin Mitchell: Is it a worry in that, in so far as GP consortia are a bunch of financially motivated doctors, to pass power to GP consortia is going to be damaging to cancer treatment in the sense that they're obviously going to be concerned to divert money away from hospitals, where most of the treatment of cancer occurs and into their own practices. Secondly, they're not going to be perhaps as generous in authorising the expenditure of expensive drugs for cancer treatment to keep me alive for another two or three months, so I'm going to spend the last two or three months of my life walking up and down outside Dr Snapple's surgery with a sign saying "Dr Snapple is killing me?" Is it going to cut down expenditure on expensive drugs and treatment in hospitals?

Professor Sir Mike Richards: If I take first of all the expensive drugs issue, you are probably aware that this Government has set up currently what's called an interim cancer drug fund and from next April there

will be a cancer drug fund of £200 million a year, so that for the new drugs that are not recommended by NICE, there will still be that pot of money, and I think there is still consultation going on about how that pot will be managed.

Q92 Austin Mitchell: But my guess would be I'd be less likely to get those drugs in Grimsby than I am in London.

Professor Sir Mike Richards: I would not think that is the truth at all, because at the moment we are allocating on a fair share basis by SHA. We will find ways through the commissioning board of making sure that Cancer Drug fund is well used across the country. So I think for the expensive drugs and, as I understand it also, for those drugs that are recommended by NICE, there will be still be the same financial commitment that, if they've been approved by NICE in the same way as they're currently mandated that the PCTs must fund them, I think the same arrangement is going to continue—I imagine it's going to continue—with the consortia. So I don't think we need to worry from the expensive drugs point of view.

Your second point was about shifting services to the community. There are some services that would be well shifted to the community. There are some patients, for example, who could receive their chemotherapy much closer to home, and if GPs decide through consortia that they want to purchase those services, that can be done. I have no reason to think that that shouldn't be done. Equally, quite a lot of the follow-up care of cancer patients can be organised better and we can reduce the follow-up care overall by empowering the patients, and we've got a programme called the National Cancer Survivorship Initiative that's looking at that. So some of that shift to the community may actually be a good thing.

Austin Mitchell: Thank you.

Q93 Stephen Barclay: Just a question on management consultants, just to try and get a bit of clarity from you, Sir Mike, in terms of what the Department has spent on management consultants as part of this Strategy. If you could give us some sort of idea of what's in the budget for the next year?

Professor Sir Mike Richards: I do not have a figure for what we spend on management consultancy.

Chair: You're talking about Cancer Pathways.

Q94 Stephen Barclay: Yes, Cancer Pathways and the world-class commissioning programme. It shouldn't be a surprise to the Department, because I tabled a parliamentary question on it a little while ago, but it's not been answered.

Professor Sir Mike Richards: I do not have that; I will have to come back to you on the figure about what we spent specifically.

Q95 Stephen Barclay: Sure. If we could perhaps have a note on that, it would just be interesting to know. Certainly, in the hearing we had a couple of weeks ago, looking at £1.5 billion of spend by Government on consultants, the Department that spent the most was the Department of Health, so it would

be interesting in terms of looking at some of the gaps in information and the way that the National Cancer Network has worked just to know what's been spent on consultants.

Professor Sir Mike Richards: We will certainly come back to you with a note on that. Where we have used management consultants on the whole it has been to drive up our information and the modelling information around, for example, what the value would be of earlier diagnosis; what the cost per poly would be of earlier diagnosis. We have commissioned research in that area; we've also had management consultancy support in terms of international benchmarking in trying to get an up-to-date picture of what's happening internationally. So I believe we have used management consultants well, but have I got a figure in my head for the figure? No, I haven't.

Q96 Stephen Barclay: Could we perhaps have note on that and a breakdown of what it has been spent on as well.

Professor Sir Mike Richards: Yes.

Q97 Stephen Barclay: Just on a separate point, in this area there's a lot of tremendously good work done by the charitable sector. I was just interested to know whether the Department has a strategy for what happens where charities get into trouble and there's gaps in provision compared with what they were providing before in particular parts of the country. I know this was an issue that came up in Wales a little while ago and a recommendation that went to the Welsh Assembly was to have a strategy in place in terms of Wales. I was just wondering whether there is a strategy for England that picked up on that issue.

Professor Sir Mike Richards: I'm sure many charities are facing difficulties in harsh financial climates, but in fact the charities that I work with, I'm very pleased to say, on the whole have been doing extremely well considering the circumstances. We work very closely, particularly with three major charities, but a whole lot of other charities; that's Cancer Research UK, Macmillan and Marie Curie Cancer Care. All of those charities contribute very, very significantly to the overall National Cancer Programme and I consider them as partners with us on that.

Q98 Stephen Barclay: Sure, but I'm referring to Cancer Care Wales, which led to a review of cancer services for the people of Wales that went to the Assembly and that recommended that a strategy be put in place to maintain the vital work performed by cancer nurses. I was just wondering, given that that was an issue looked at by one of the devolved assemblies, whether that was picked up vis-à-vis England.

Professor Sir Mike Richards: I haven't actually come across that issue in this country, and I hadn't come across the report from Wales, but I would be very happy to look at it.

Q99 Chair: I'm going to draw this to a close. I think this has been a very productive session; I just wanted to cover two or three more areas very quickly. Professor Richards, you mentioned the survivorship

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plan; could you just say a little bit more about that: how much it's going to cost; what it's going to deliver, and by when?

Professor Sir Mike Richards: Yes. The whole idea of the survivorship initiative is to look at that phase after patients have been through primary treatment, where we're therefore trying to work with them to get them back to as normal and healthy a life as possible. In the past, we have tended to have a one-size-fits-all model of follow-up and you come every three months for the first year, then every four months, then every six months, and a lot of that follow up is frankly not providing the care that patients need or want.

We want to do things very differently. We've been working on this in partnership particularly with Macmillan Cancer Support, but also with others. We recognise that critically at the end of treatment what patients need and want is a full assessment at that point; to be given a record of the care that they've already received; and then to be advised about what might lie ahead for them and given advice on what to do about it. With that care planning we can then help them to get back to a normal life.

For example, there is now very good evidence that physical exercise after you've had cancer reduces your risk of recurrence. Now, that was not known when I first became national cancer director. That's advice we now need to be giving to all patients, to GPs, to make that widely known, because it's a very inexpensive way of making sure that patients get the very best chance of survival. So we're doing a lot of work on that area. Overall, our best estimates on this are that by providing better care in this way but by reducing routine follow up this should broadly speaking be cost neutral. We're not expecting this to be a major new cost on the health service. We think we can do better but without costing more.

Q100 Chair: Also I'd just like to return briefly to the question of staging data, because apart from chemotherapy I think you said that this is one of the most important challenges that you face. When do you think—this speaks to figure 6 in the report, which shows how much variation there is in cancer registries—this chart will give us the sort of information we need, basically with each bar being at roughly 100% for each area of the country?

Professor Sir Mike Richards: You will probably never get to 100%. I don't know any country that manages that.

Q101 Chair: What would be for you, in terms of managing this, an acceptable figure—between 90 and 100?

Professor Sir Mike Richards: No, honestly, I think the Eastern Registry is about where one gets to.

Q102 Chair: All right. When are they all going to get up to the level of the best?

Professor Sir Mike Richards: I would hope to get there within two years.

Q103 Chair: Right. It would be a shame to have you in front of us and not ask about aspirin, since it was on the radio this morning.

Professor Sir Mike Richards: It would, wouldn't it?

Chair: The interesting phrase in the BBC report that I was looking at said, "by dusting down the data," and then following up the patient health records, which I thought was interesting. And it said the researchers then came up with some remarkable results, suggesting that what we've been talking about in terms of the quality of data could reveal yet more interesting things if only it were more consistently available. What are the public to make of this, because we have a Professor Alastair Watson, who's an expert in translational medicine at the University of East Anglia and therefore presumably a good egg, who says that while people who wish to take aspirin should discuss it with their GP, it's nonetheless further proof that aspirin is by a long way the most amazing drug in the world. We also have Professor Sever, who's Professor of Clinical Pharmacology at Imperial College, saying, "We have to remember that aspirin is not a safe drug and it causes harm, and until such time as we know what the numbers are—how many cancers are prevented against how many people suffer significant bleeding—then we cannot answer that question." He goes on to say, "We do not know for example what the effect of very long term use of aspirin might be." What are the public to make about all of this and what are they to do?

Professor Sir Mike Richards: Well, I think this is an extremely encouraging trial or study. Basically, what they have done is to put together information from eight different trials. Incidentally, these trials were done for using aspirin in a completely different context. These were trials looking at whether the use of aspirin could reduce heart attack and strokes, which it can. And this is very low dose aspirin—75 mg a day. The average aspirin tablet that we all may be familiar with is 350 mg, so it's one fifth of that. So it's a low dose.

There are side affects; you can get stomach bleeding from aspirin at any dose, so that does have to be weighed against the benefits, but I think what we now know is that there are benefits, not only for heart disease and stroke, which have been shown before, but there are benefits for cancer; roughly speaking a 20% reduction in mortality. Now, I have only had 24 hours to look at this paper; I've read it with great interest. I certainly now want to get together with a whole lot of experts to look at it in more detail to get their views. I then want to be saying what further research is needed if any: can we get to the point that one of the gentlemen that you quoted said, of being able to calculate how many people might get stomach bleeding, how many people might be prevented from getting cancer or dying from cancer? We need to do that work, but I think this will stimulate us to do it.

Q104 Chair: Thank you. Finally, and while we're on the subject of better information, I'd just like to ask the question of Christine Connelly since you're here: you're about to sign a memoranda of understanding with CSC to rewrite the LSP contracts for the national programme for IT in the health service for which you've got a discount, I think, of several hundred million pounds. Can you say how many hospital trusts

you're expecting to cover with that new memoranda of understanding?

Christine Connelly: So the contract that we have with CSC, you're talking about the LSP contract for the North, Midlands and East.

Q105 Chair: The memo of understanding is, essentially as I understand it, to overwrite the existing LSP, or it's another kind of contract reset in a sense, is it?

Christine Connelly: It's not to overwrite the existing contract. So there's one overall exercise going on across Government, which is to look at all IT suppliers and all contracts that we have. As part of that each Department that holds a significant contract with any IT supplier has been asked to take a look at their contracts. The other exercise, however, is around the national programme for IT, where we were challenged to reduce the overall cost of the programme and within that we had originally a plan that would have reduced the cost of the CSC contract by around £300 million. The new coalition Government asked us to go further than that and look for savings of £500 million on that contract.

The way that we expect to achieve those savings are first of all to look at the functional points that are delivered by CSC in that contract and the number of trusts that they deliver to. So by combining the functionality delivered, for example, by removing GP systems from that contract, principally because GPs say that they are happy with the systems they've got and they are not looking for a full replacement system, which would have been part of the value of that contract, and reducing the number of trusts who would take systems—for example, in acutes for Lorenzo—that whole mix together will potentially save us £500 million.

Q106 Chair: How many hospital trusts do you think are going to take Lorenzo?

Christine Connelly: I don't know that number off the top of my head; I'm sorry I didn't bring that with me in terms of today.

Q107 Chair: How many trusts?

Christine Connelly: In terms of the total number of trusts that we expect to come down, we expect that to be in the range of about 35. I can't tell you whether

that's all acutes or whether some of those are community trusts. I would need to go away and check that.

Q108 Chair: How many of the hospital trusts which might be in that universe have already signed contracts to take alternative systems because they've decided that Lorenzo isn't suitable for them?

Christine Connelly: Actually I don't know that. What I can tell you is that in the summer we went out to all of the trusts through the Strategic Health Authorities and asked each trust to confirm whether they intended to take the systems offered under the CSC contract. Not all the systems are Lorenzo; so there's an ambulance system and TPP is offered underneath that contract, which is why I'm trying to get that table in my head. So we asked all of those trusts to confirm their position. So through the summer they did and we reduced then our expectation on the number of trusts that we would have by about 35 as a result of that exercise.

Q109 Chair: But you reduced it by 35?

Christine Connelly: Of that order.

Q110 Chair: To how many?

Christine Connelly: I need to check these numbers and get that back to you, Chair, but my recollection is that we have about 222 trusts covered in the CSC contract and we would expect to reduce that by about 35.

Q111 Chair: All right. I don't really want to wait for further answers on this until next March, although I fear I may have to. This has been a very useful session. Professor Richards, thank you very much. One thing that we've not covered is what role you see for yourself in the new reformed world. Would you like to comment on that, or would you like to plead the fifth?

Professor Sir Mike Richards: I would just be very happy going on doing what I'm doing if people think it's useful.

Chair: Well, I think certainly so far you've impressed this Committee, and we're delighted for your attendance to day. Thank you all very much indeed.

Written evidence from Cancer Campaigning Group

The Cancer Campaigning Group (CCG) is a coalition of over 45 national cancer-related charities representing service providers, research, advocacy and campaigning groups for cancer patients and their families. We campaigned for the introduction of the Cancer Reform Strategy (CRS) in 2007, and welcomed the NAO's finding that progress has been made as a result of the Strategy, and under the leadership of the National Cancer Director, Professor Sir Mike Richards. We believe that it is vital that momentum in service improvement is maintained to the benefit of cancer patients and their families, despite the current financial climate. However, we are concerned by a number of the findings of the report and would be keen for the Committee to ask witnesses about how they plan to urgently address the following priority areas:

Availability of Staging Data

Many people still present to their GP with their symptoms at a late stage by which time their cancer is already advanced. Diagnosing more patients at an earlier stage in their disease would expand the range of treatment options available to them and increase survival rates. We are concerned that the NAO identified that

staging data is collected in fewer than 35% of cases in England, and that this varies from less than 15% at the North West Cancer Intelligence Service to almost 70% of cases in the Eastern Cancer Registration and Information Centre. The CCG believes that staging data should be collected in all cases, and that GPs should be incentivised to diagnose patients at an earlier stage.

One Year Survival Rates

The CCG supports the introduction of a one year survival indicator as a way of tracking progress on early diagnosis, and is pleased that this measurement looks likely to be included in the NHS Outcomes Framework. However, it will be important that data on one year survival rates is available in a timely manner so that it can be of use to commissioners.

Emergency Admissions

We are also concerned that the number of emergency admissions for cancer has continued to rise since the introduction of the CRS. The report shows that between 2006–07 and 2008–09, emergency admissions have increased from 289,000 to 300,000. Emergency admissions not only represent a significant and often avoidable cost to the NHS, but also have a negative impact on patient experience. It is clear that more has to be done to ensure that emergency admissions are reduced, though earlier diagnosis, appropriate referral and the closer monitoring of cancer patients during and after treatment. In particular, we believe that enabling more cancer patients to self-manage their condition, supported by cancer nurse specialists, can deliver efficiency savings while also improving patients' experience of care.

Ongoing Review of Progress

We hope that the issues identified above, and others raised in the NAO report, will be addressed within the review of the CRS currently underway (and to which the CCG has submitted a formal response). We believe that it is vital that progress on these and other issues continue to be measured. We would therefore strongly advocate the NAO reporting again on this issue within the next three years, and hope that this is something that the Public Accounts Committee would support.

We hope that you will be able to address these issues in your evidence session and report, and would be very happy to provide more information if required.

30 November 2010

Written evidence from Cancer Research UK

I have recently been contacted by one of my patients, who has requested that I write a letter to you regarding my views on the early detection of prostate cancer by means of measurement of prostate specific antigen (PSA) in the blood. I should stress that I am writing to you in my capacity as his Consultant rather than in any of the other roles I hold.

At present in the United Kingdom around 30,000 men each year are diagnosed with prostate cancer and every year 10,000 or so die of the disease. The reason why men die of this cancer is that in its later and more advanced stages it spreads to other parts of the body, particularly the bone where it can cause very unpleasant symptoms of pain and can cause obstruction to the urinary system and kidney failure. The options for managing this later form of the disease are presently limited. Many men with more advanced prostate cancer undergo hormonal treatment which involves the reduction in the levels of the male sex hormone in the blood. This too produces very many side effects of lack of energy, muscle weakness and of course sexual problems. We also know now that hormonal treatment over a long period can increase the risk of heart disease and bone fractures. Unfortunately such treatment of advanced cancers is usually time limited and the disease recurs and in its later forms it is resistant to further forms of androgen ablation therapy.

There is of course a lot of research going on to try and find ways of treating this more advanced cancer and prolong patients life and the UK has been very successful in this respect with a new drug coming out of the Institute of Cancer Research led by Dr Johan De Bono, which has improved the life expectancy of men.

Prostate cancer in its earlier stages does not cause any symptoms and can only be detected at present by means of a careful examination of the prostate carried per rectum (digital rectum examination or DRE) or by measurements of a protein which is produced by the prostate called prostate specific antigen (PSA). The number of men who undergo PSA testing in the United Kingdom is incredibly low by International standards. The latest evidence suggested about one in 12 men have undergone a PSA test and around one in 10 to one in eight men know what a PSA test is. There is a huge amount of ignorance and lack of information both amongst the general public but also regrettably in primary care amongst General Practitioners.

There are a number of problems with the PSA test. Firstly, if a man has a level which is regarded as increased or raised for his age that man then has to undergo a prostate biopsy which is somewhat invasive and involves the insertion of an ultrasound probe into the rectum and the performance of around 12 to 18 prostate

biopsies. We think that things will improve here in that better forms of imaging or better biomarkers in the blood and urine will enable a more accurate diagnosis to be made.

There are also problems with the PSA test itself in that there is really no level at which a man can be guaranteed to be free from prostate cancer. We know that men with very low levels of the PSA can still have risks of prostate cancer.

Also regrettably the prostate biopsy itself is not completely accurate in that some small cancers can be missed on first biopsy and some men require second or third biopsies to be carried out, although once again better biomarkers are available.

I enclose below some bullet points which I believe are proven through research which I hope are helpful and I have expanded them below at each section for your further information.

1. *Early detection of prostate cancer by means of PSA testing saves lives*

There is no question from studies carried out in Europe in the past few years that early detection saves lives. There is debate about the number of lives saved for each 100 men who undergo a PSA test but the levels would vary somewhere between one life saved for between 15 and 40 men who are diagnosed with prostate cancer.

2. *Whilst PSA testing saves lives it also detects many cancers which are of low risk to the patient*

Not all prostate cancers are killers. Some are very small and are of low pathological grade (Gleason Grade of 6 or less).

Many of these small cancers will not progress during a man's lifetime which means that some men with these low risk cancers can be managed expectantly by programmes known as active surveillance or active monitoring. In other words not all screen detected prostate cancers require surgery or radiotherapy treatment. At present we do not have a very accurate way of identifying these cancers but progress again is being made through research funded by the Department of Health and the MRC and Cancer Research UK to identify better biomarkers.

3. *The evidence is not strong enough for Urologists and the Government through the Department of Health to recommend a National Programme of Screening*

Because of the lack of sensitivity and specificity of the PSA test (in other words it misses some prostate cancers and some men with a high PSA turn out to have a benign prostate), because of the risks and discomfort of men having to undergo invasive prostate biopsies, because screening picks up many small cancers that are relatively innocuous and because prostate cancer is relatively slow growing the evidence is not good enough to recommend a National Programme of Screening.

4. *Men should know about the PSA test and should be able to undergo a PSA test by their General Practitioners*

The current stance of the Department of Health is that men who request a PSA test should be given one although should be counselled about the pros and cons as outlined in my letter above. This was reinforced by a letter which went to all General Practitioners from the Chief Medical Officer some years ago. Unfortunately research carried out by Prostate Cancer Charities shows that there is a high level of ignorance and lack of understanding both amongst the general public and in primary care. Only about 12% to 15% of men aged between 50 and 65 actually know what a PSA test is and we also know from research that men who go along to their general practitioner to request a PSA test may be turned away by a GP who is not willing to order the test for a variety of reasons. We think that somewhere around 15% of General Practitioners would refuse a man a PSA test even if they requested it.

5. *What is required to be done now*

I believe now that all men aged between perhaps 40 and 65 should know what the PSA test is and should be able to access information easily which describes the pros and cons of PSA testing and early detection. If after due consideration they wish to have a PSA test and wish to undergo a prostate biopsy then they should be able to do so by the NHS. We know at present that this is not happening. I believe that we do require a programme of education which is targeted to General Practitioners. I believe that all men aged between 40 and 65 should receive a leaflet outlining the points I have raised above. There probably also needs to be different programmes targeted at those men at increased risk. For instance we know that men with a positive family history and we know that men of Afro-Caribbean origins are at much increased risk and there may be a number of initiatives which are required to target these men perhaps drop in centres in their local communities or a more active programme of information given at their work place.

In other words I would conclude by saying that I do not think the evidence is strong enough to recommend a Department of Health led programme of screening but I do believe that the evidence now demonstrate that early detection will save some lives and therefore men should know about it and should be able to access the PSA test.

The present programme put forward by the Department of Health we know is not working and something does need to change.

20 December 2010

Written evidence from Ovarian Cancer Action
BRIEFING PAPER FOR PARLIAMENTARIANS

Introduction

Ovarian Cancer Action¹ is the UK's leading ovarian cancer charity. The charity is dedicated to improving the poor survival rates for women diagnosed with ovarian cancer in the UK by raising awareness of the disease, funding research at the Ovarian Cancer Action Research Centre and giving a voice to women affected by the disease.

Ovarian Cancer Action is dedicated to advancing and supporting ovarian cancer research as part of its mission to save women's lives. We are an independent charity who funds a broad range of research to achieve accurate and early detection of ovarian cancer, more effective treatments as well as preventative measures to combat the disease.

The Importance of Early Detection

Most women diagnosed with ovarian cancer experience symptoms, even in early stage disease, when survival rates can be as high as 90%. Yet in this country, three out of four women are only diagnosed with ovarian cancer once it has spread beyond the ovaries, when survival rates fall dramatically.

Key Facts

- Ovarian cancer is the fifth most common cancer in women, and the biggest gynaecological killer in the UK.
- Every year, 6,800 women are diagnosed with ovarian cancer.
- Only 38% of women diagnosed with ovarian cancer will survive five years beyond a diagnosis.
- 12 women die from the disease each day.

UK survival rates have not improved in 20 years, remaining low at 38%, compared with an increase to 79% for breast cancer.

There is currently no proven national screening tool for ovarian cancer. Women often mistakenly believe ovarian cancer will be detected by a cervical smear. The fact is we are still years away from conclusive and informative answers on national screening. Therefore, it is vitally important to raise awareness of the symptoms among the general public and healthcare professionals.

Focused research undertaken at the Ovarian Cancer Action Research Centre will eventually improve our understanding of what causes ovarian cancer and the most effective ways of treating and diagnosing it but, in the meantime, a greater awareness of the symptoms of ovarian cancer amongst the public, healthcare professionals, parliamentarians and the media, provide our best hope of ensuring more women are diagnosed at an earlier stage—when the disease can be treated more effectively.

Raising Awareness of Ovarian Cancer

Ovarian Cancer Action's * Remember the symptoms campaign is the UK's first national ovarian cancer symptoms awareness campaign. The campaign is aimed at raising awareness of the common symptoms of ovarian cancer and encouraging women to share this information with the other women in their lives. Raising awareness will improve women's chances of the disease being diagnosed earlier—before it has spread beyond the ovary.

We recently launched our online campaign "Every woman should remember" and so far 1,846 people have taken the pledge to remember the symptoms of ovarian cancer. We are working with health professionals, parliamentarians and policy makers to ensure that more people take the pledge to remember and improve women's chances of surviving the disease.

Call to Action!

Many women with ovarian cancer are passionate about improving awareness to achieve earlier diagnosis. Ovarian Cancer Action shares this passion, and works with women to tell their stories and experiences.

Ovarian Cancer Voices provides a platform for women and their families affected by ovarian cancer to share their experiences with others. Ovarian Cancer Action is keen for women who have been diagnosed with ovarian

¹ Ovarian Cancer Action is a member of the Association of Medical Research Charities—a membership organisation of the leading medical health and research charities in the UK.

cancer to voice their experience. These individuals can offer valuable knowledge and insight into symptoms, diagnosis, and treatment of the disease. This information is used to support the charity in its development of services, ensuring we are meeting the needs of women and their families affected by the disease.

We are calling on all parliamentarians to become Ovarian Cancer Action Champions and ensure that ovarian cancer is a priority for all political parties. With your help we can ensure that millions more women and health professionals will know about the symptoms of ovarian cancer and take action to combat the disease, which has been known for far too long as the *silent killer*.

ISBN 978-0-215-55664-6

