

# CANCER SERVICES: REVERSE, PAUSE OR PROGRESS?

**The NHS reforms and efficiency savings: an early assessment  
of the impact on cancer services in England.**

A report for Cancer Research UK by the Health Services  
Management Centre, University of Birmingham.

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# EXECUTIVE SUMMARY

## INTRODUCTION

In July 2010, the Government unveiled plans to significantly reform the structure and organisation of the NHS in England. Changes were introduced to the NHS at every level in both service provision and commissioning. This came just over a year after the NHS had been set the unprecedented financial challenge of finding up to £20 billion in efficiency savings by 2014–15.

This report presents the findings of research commissioned by Cancer Research UK to assess the early impact of both the health reforms and NHS efficiency savings programme on cancer services in England. The research comprised two main activities:

- An analysis of trends in cancer waiting times, diagnostic waiting times and expenditure from April 2010 onwards
- Qualitative interviews with key stakeholders to explore views and experiences at both national level and in eight cancer network areas.

More than 50 in-depth interviews were carried out between April and August 2012 with a wide range of participants including policymakers, clinicians, cancer network staff, senior managers, primary care trust (PCT) and clinical commissioning group (CCG) commissioners, public health experts and patient representatives. Networks were selected to ensure a variety of socio-demographic, environmental and service-related characteristics. Geographical coverage was ensured by selecting two networks from each of the four Strategic Health Authority regional clusters.

The full scale and effect of the reforms will not be known for many years yet. The findings, which provide an early insight into the impact that they and efficiency

savings may be having on cancer services in England and the data gathered, tell a mixed story.

Performance of cancer services against national waiting time standards has – for many indicators – held or even slightly improved over the last two years, despite increasing numbers of patient referrals. The main exception to this is waiting times for endoscopic diagnostic tests, which started to increase in mid 2010 and have yet to return to previous levels.

But performance data do not reveal the full picture. Interviews with national and local stakeholders raise questions about the cost at which service performance is being held, as well as long-term sustainability of services.

Several themes dominated interviews, including concerns about local and national fragmentation, loss of cancer knowledge and expertise, the difficulty of developing and improving services in a climate of ongoing uncertainty and poor staff motivation and morale. While there was a widespread feeling that cancer may be more insulated from funding pressures than other areas, it appears that some services are soft targets for cuts, including administrative and clinical nurse specialist posts and rehabilitation and support services.

Several interviewees felt that these and various other factors have stalled improvements in cancer services, with estimates given of anywhere between 18 months to 3 years for recovery to occur. There is a pressing need for greater clarity about roles, responsibilities and accountabilities within the new system architecture. This is essential to overcoming the barriers to long-term and coordinated planning which cancer professionals and staff are currently contending with.

## TRENDS IN CANCER SERVICE PERFORMANCE AND EXPENDITURE

Although the number of patients referred by their GP with suspected cancer has risen substantially in recent years, services have continued to perform well against the 2 week, 31 day and 62 day targets. Access to diagnostics shows a more varied picture, with significant increases in the number of patients waiting more than six weeks for a diagnostic test during 2010 and 2011. Waits have subsequently returned to previously seen levels for radiological imaging tests, but have yet to do so for endoscopic tests.

Over much of the 2000s, real-terms expenditure on cancer services grew year-on-year. But the most recent data show a reversal of this trend.

### 1. Diagnostic tests for cancer

As more patients are referred for suspected cancer, the number of diagnostic tests has also increased. The total number of tests performed increased by approximately 5% each year in 2010–11 and 2011–12. The two largest categories of diagnostic tests are radiological imaging investigations (MRI, CT and non-obstetric ultrasound), which represent 70–72% of all tests performed, and endoscopic tests (colonoscopy, flexisigmoidoscopy, cytology and gastroscopy), which account for just under one in ten (9%) of all tests performed.

Over the last two years, the proportion of patients waiting more than six weeks for a diagnostic test has fluctuated substantially. There was a marked decline in waiting times for imaging tests between December 2010 and mid 2011, but waits have subsequently recovered to more normal levels. A similar pattern can be observed for endoscopic tests, with waiting times steadily increasing from summer 2010 and peaking in May 2011. While there has been some improvement in endoscopic waiting times more recently, they have not yet returned to previously seen levels. The data on patients waiting more than 13 weeks mirrors the movements in the six week wait data.

### 2. Cancer waiting times

The number of patients referred to specialist services with suspected cancer has grown in recent years. In 2011–12 there were 1.1 million urgent patient referrals, some 10.3% higher than the previous year. Despite this increase in demand, the speed at which patients accessed services was sustained and, in some cases,

improved over the same period. In April–June 2010, the two week wait target was achieved for 95.5% of all patients referred; by March 2012 it had reached 96.3%. In both 2010–11 and 2011–12, treatment was initiated within 31 days of a positive cancer diagnosis for 98.4% of patients.

### 3. Expenditure on cancer services

In recent years there has been significant investment in cancer services in England. Real-terms expenditure on cancer rose by 2.9% in the 2008–09 financial year and by 11.2% in 2009–10. However, data for 2010–11 show a 2.6% real-terms decrease in cancer spend due to a combination of low nominal growth in total expenditure, a small reduction in the proportion of the NHS budget allocated to cancer and high inflation. In the same financial year, the money spent on cancer services per head of the population declined in real terms by 3.4%.

## VIEWS AND EXPERIENCES OF THE HEALTH REFORMS AND EFFICIENCY SAVINGS

The most dominant theme from cancer services staff interviewed was that the reforms were starting to cause fragmentation of cancer services. Concerns were also raised about CCGs accessing cancer knowledge and expertise to commission services and the implications this might have for further progress in integrating pathways of care and improving the patient experience. Transferring public health to local authorities was expected to create risks and opportunities. A stronger national focus on awareness and early diagnosis was widely acknowledged, but many interviewees argued that recent campaigns had put additional pressure on already stretched services.

### 1. Scale of change

The current changes to the NHS are of a different order and scale than previously seen. The sheer scale of the reforms with changes being implemented and felt at the local, regional and national level across commissioning, provision and public health has created a situation where there were ‘no islands of serenity’. The challenge of implementing far-reaching changes had been compounded by the absence of a clear policy narrative and an ongoing lack of clarity about major aspects of the reform programme.

Uncertainty about roles, relationships and accountabilities in the new system architecture, and the future commissioning arrangements for cancer services, were common sources of concern.

## 2. Financial austerity

Alongside the issue of the scale of the reforms was their introduction at a time of financial austerity. The NHS has periodically implemented government reforms or made financial savings, but it has never before been asked to achieve these at the same time. Finding £20 billion savings through productivity improvements would require large-scale service redesign, not just the identification of 'quick wins'. There was a widespread sense that the capacity and skills to undertake this kind of work was being jeopardised by the disruption which the reforms had created locally.

## 3. Fragmentation

One of the main outcomes of the health reforms will be a substantial increase in the number of organisations involved in planning, commissioning and delivering cancer services. Particular concerns were expressed that, in place of 152 PCTs, there will be public health teams based in local authorities, approximately 220 local commissioning bodies (CCGs) and an as yet unspecified number of commissioning support organisations. The issue of whether and how CCGs will collaborate across boundaries to ensure a consistent and integrated approach to cancer care was also raised.

Interviewees were starting to observe fragmentation in both the commissioning and provision of cancer services, as well as in national policy and oversight bodies. Many interviewees felt that the development of a nationally coordinated approach to cancer, under the high profile leadership of Sir Mike Richards, had played a pivotal role in driving improvements in cancer services over recent years.

## 4. Local leadership

This linked to a broader concern about who would be providing local system leadership and coordination given the abolition of PCTs and strategic health authorities (SHAs) and reduction in the number and capacity of cancer networks. While views about cancer networks varied, many applauded the expertise and support they had provided to plan and improve local services and facilitate joint working. Interviewees felt that networks with fewer staff covering larger geographical areas would struggle to retain the local knowledge and engagement that was vital to their success.

## 5. Planning blight

The experiences shared indicate that, in the transition to the new system, a decision-making vacuum has emerged which is causing planning blight. A strong theme in many of the interviews was that a 'gap in the middle' was opening up with the move towards a larger number of more localised commissioning bodies and a smaller number of more distant regional bodies.

Long-term strategic planning is proving a major challenge, and several examples were given where uncertainty about who has the authority to make decisions and sign off budgets had negatively impacted on service development. Interviewees believed further improvements in cancer services would be stalled for anywhere between 18 months and 3 years.

## 6. Expertise to commission cancer services

Interviewees were broadly positive about having greater clinical and primary care involvement in commissioning, and potential benefits include better engagement across primary and secondary care and a strengthened focus on aspects of the cancer pathway that are most relevant to primary care.

However, interviewees expressed doubts about whether GPs possess a sufficiently detailed understanding and knowledge of cancer to commission services effectively at a local population level. Concerns were expressed that CCGs and GPs did not fully understand pathways of cancer care because they predominantly saw cancer as a 'secondary care issue' or a 'referral issue'. There was therefore a risk that GPs may focus attention on redesigning specific parts of the patient pathway (e.g. referrals, follow-ups) in isolation, rather than looking at cancer services across the patient pathway, particularly given the pressure on them to make cost savings. In some areas, specific services were being targeted in a way that was variously described as 'dibbling and dabbling', 'tinkering' and having 'pet projects'.

Concern was also expressed by a number of interviewees about how to source the necessary knowledge and expertise to commission cancer services, especially at a time when many experienced colleagues had left the NHS, cancer networks were being substantially reduced in size and public health was moving into local authorities.

## 7. Impact of the reforms on the cancer workforce

Many interviewees felt that cancer had been relatively protected from financial cutbacks in comparison to other clinical areas. They agreed there was scope for cancer care to be provided more efficiently, and this has been a key driver of local pathway redesign.

The push to achieve efficiency savings appears to be affecting cancer services in several ways, not all of which were welcomed. In addition to post freezes and redundancies reducing capacity and increasing workload pressures, certain services – including clinical nurse specialists and rehabilitative and support services – are soft targets for spending cuts. This raises questions about the impact that efficiency savings may be having on the cancer patient experience as well as on outcomes.

## 8. Public health

Interviewees welcomed the focus on cancer prevention and early diagnosis and the vital role public health teams contribute to this agenda. Concerns were raised about the pressure the electoral cycle may place on local governments to demonstrate short-term outcomes and may discourage strategies where health improvements would only be realised in the medium to long term.

Concern was also expressed about a possible loss of focus on the medical aspects of public health practice which are central to cancer prevention. Local authorities would take a broader view of public health than Primary Care Trusts (PCTs) had done, integrating areas such as housing, employment, transport and regeneration.

## 9. Research and clinical trials

Some interviewees stated that because of the lack of appropriate numbers of staff clinics, the time spent with each patient was limited. Cancer services teams were having great difficulty doing the extra things which make a good service which are important, such as setting up clinical trials.

## CONCLUSION

The findings in this report present a mixed picture. The performance of cancer services against national waiting time standards has – for many indicators – held or even slightly improved over the last two years, despite increasing numbers of patient referrals. However, policymakers, professionals and patients share a number of concerns about how the reforms and efficiency savings are affecting cancer services and patient care. The insights from interviews raise questions about the cost at which service performance is being held, as well as the long-term sustainability of this situation.

There is a very real possibility of fragmentation in cancer services at both a local and national level. There is a need to ensure that the right structures, levers and incentives are in place to enable and encourage joint working. Equally, the issue of who will provide the local system leadership and coordination on which integrated models of cancer care depend must be addressed. These should be urgent priorities for NHS leaders and policymakers as implementation of the reforms progresses.

# INTRODUCTION

In July 2010, the Government announced far-reaching plans for health reform, a central aim of which was to give local NHS organisations greater freedom from political interference and centralised control. Since that time, the NHS has been undergoing unprecedented structural and organisational change.

The new NHS architecture is expected to be in place and operational by April 2013. Key changes include the:

- establishment of an arm's-length NHS Commissioning Board (NHSCB), with responsibility for allocating resources across the NHS and accountability for the outcomes achieved
- abolition of Primary Care Trusts and Strategic Health Authorities
- creation of four NHSCB regional offices, 27 local area teams and 12 clinical senates
- organisation of general practice into clinical commissioning groups, responsible for local commissioning of healthcare services
- transfer of public health into local government.

In 2014, the NHS will have to reduce its management costs by 45% and overall administration costs by 33%.

Implementing changes of this scale would be demanding for a health service to achieve in any circumstances. But for the NHS, they come at a time of considerable financial challenge and uncertainty. While the NHS was largely protected from the major cuts to Government departments outlined in the 2010 public spending review, it is nonetheless required to deliver efficiency savings of up to £20 billion by 2014–15 – the biggest savings programme in the history of the NHS.

Such gains in productivity cannot be made through short-term fixes or the identification of 'quick wins'. Rather, it demands radical changes in the design and delivery of services and patient care pathways. At a time when the entire health service is in transition and the expected increases in cancer patients as the population ages, it has never been more important for providers, commissioners and patients to work together to bring about lasting improvements in the quality and outcomes of cancer care.

This report examines what impact the efficiency savings and implementation of the health reforms have had on cancer services in England. The timescales for the completion of these changes have not yet been reached, and there is arguably still much at stake. Therefore, the time is right to make an early assessment of what difference the reforms and efficiency savings are making to services, professionals and patients and anticipate likely future benefits and risks.

Cancer Research UK commissioned an independent research team from the University of Birmingham's Health Services Management Centre to carry out the evaluation. Alongside analysing recent trends in cancer services performance and expenditure, qualitative research was undertaken to explore the views and experiences of key stakeholders. More than 50 in-depth interviews were carried out between April and August 2012 with a wide range of participants including policymakers, clinicians, cancer network staff, senior managers, PCT and CCG commissioners, public health experts and patient representatives.

The report is organised into five main sections, including:

1. a review of recent developments in cancer policy and services
2. a summary of the changes currently being implemented in the NHS as a result of efficiency savings programmes and health reforms
3. trends in cancer waiting times, diagnostic waiting times and expenditure
4. findings of the qualitative research, which are organised around a series of themes, each of which is illustrated with quotations from the participant interviews
5. implications of the research in light of wider evidence about the impact of large-scale change on organisational behaviour and performance.

# KEY DEVELOPMENTS IN CANCER POLICY AND SERVICES SINCE 1995

Cancer services in England have significantly changed since the publication of the Calman-Hine Report in 1995 which highlighted discrepancies between spending on cancer services in the UK and other developed countries and the wide variation in cancer outcomes (Calman and Hine 1995). Targeted policies and programmes over the intervening 15 years have seen stronger investment, increased capacity in workforce and facilities, development of national pathways, introduction of national standards, targets and screening programmes, and the establishment of a number of mechanisms to drive improvements and provide expert advice and support. In the most recent National Cancer Patients Experience Survey, 88% of respondents rated their care as 'excellent' or 'very good', suggesting that cancer inpatients report significantly better experiences of care than hospital inpatients generally (Department of Health 2012).

It is estimated that cancer services received an extra £640 million of funding between 2000–01 and 2003–04 (National Audit Office 2010). Part of this investment was targeted at increasing the capacity and capability of the workforce. Multi-disciplinary teams (MDTs) were established to bring together all the relevant experts to plan and co-ordinate care for individual patients, and these have subsequently formed the core model for the delivery of cancer services within hospitals. Numbers of Clinical Nurse Specialists (CNSs), an integral part of the MDT, have increased steadily over time. A 2010 census of CNSs in cancer care (2010) reported the total nurse workforce as 2771 whole-time equivalents (National Cancer Action Team 2010). The number of consultants in specialities with a major role in cancer also increased by 36% – from 9,700 to 13,100 – between 2000 and 2006 (National Audit Office 2010).

Cancer networks were introduced in 2000 to drive change and improvement in cancer services for the population in a defined geographical area, by bringing together all key local organisations to plan and monitor service delivery. Individual cancer networks may have interpreted their brief slightly differently but in broad terms have fulfilled the following roles (Cancer Campaigning Group 2011):

- provision of specialist commissioning expertise and advice on cancer services
- leadership to ensure coordination of services across primary, secondary and tertiary care
- guidance on how specialist cancer services should be commissioned and which bodies are most appropriate to commission them
- support in developing cancer user involvement mechanisms
- monitoring of compliance with National Institute of Health and Clinical Excellence (NICE) Improving Outcomes Guidance.

NHS Cancer Screening Programmes, the National Cancer Intelligence Network, the National Cancer Services Analysis Team, the National Cancer Research Network and the National Cancer Action Team were all established during the same period – the latter with a specific remit to develop national pathways to reflect the latest evidence and expert opinion. The post of National Cancer Director was created to lead the transformation and report directly to Ministers. A national survey of cancer patients was also introduced to track patient experiences.

Providers of cancer services have been peer reviewed against national standards since 2001. Over the decade since, additional targets have been introduced including the two-week target for urgent referrals from a GP to a

cancer specialist; the one-month maximum wait from diagnosis to treatment for all cancers; the two-month maximum wait from urgent referral to treatment for all cancers; and targets to reduce mortality rates from cancer in the under 75s. Cancer services are also required to implement Improving Outcomes Guidance (IOGs) for six specified cancers.

Subsequent Government publications such as the 2007 Cancer Reform Strategy (the then Labour government's five-year strategy) and the yearly NHS Operating Frameworks continue to promote cancer as a national health priority. For example, the 2009–10 Operating Framework introduced the target of a maximum wait of 31 days for radiotherapy, while the 2012–13 Framework requires providers to improve one- and five-year survival rates from colorectal, lung and breast cancers (Department of Health 2008; Department of Health 2011a).

In April 2011, the Government announced the creation of the Cancer Drugs Fund – a £600 million fund over 3 years to pay for cancer drugs that have not yet been approved by NICE. The decision to set the fund up was based on an analysis of 14 developed countries where the UK was ranked 12th on access to cancer drugs that had come onto market in the last 5 years. The Fund is administered by regional clinically-led panels.

Other organisations, including charities involved in cancer research and patient care, have played an important role in driving the agenda forward and delivering improvements. These include Macmillan's role in the development and training of the CNS workforce – Macmillan currently offers support for approximately one-third of CNSs in English cancer network – and Cancer Research UK in the development of the National Early Awareness and Diagnosis Initiative.

Since the publication of the NHS Cancer Plan in 2000, outcomes in cancer services have improved. The Cancer Reform Strategy reported that cancer mortality in people under 75 had fallen; survival rates for cancers such as bowel and breast cancer had seen year-on-year improvements; better preventive work had led to a fall in smoking rates; more cancers had been detected by screening; patients had benefitted from faster diagnosis and treatment; and there was improved access to certain drug treatments (Department of Health 2007). However, the strategy also acknowledged that the gap in survival rates between England and the

best European countries had not been closed and set out a series of actions to improve outcomes. Three years later, the National Audit Office's (2010) report on delivering the strategy found the following:

- aspects of cancer information have improved but key gaps and limitations remain
- few commissioners make best use of the information available when commissioning cancer services and most do not know whether their commissioning is cost-effective
- there are opportunities to deliver better outcomes for patients while saving money and freeing up resources to meet the increasing demand for services
- though there have been measurable improvements in efficiency by treating more people as day cases and reducing length of stay, there is scope to make further improvements by tackling variation and raising performance to the standard of the best.

The report also forecast that the number of new cancer cases each year will continue to rise and will reach 300,000 by 2020, placing an increased burden on services. The most recent strategy document sets out a direction for cancer services for the next five years and heralds another Government target of saving an additional 5,000 lives from cancer every year by 2014–15, in order to bring England into line with average European survival rates (Department of Health 2011).

# THE NHS REFORMS AND EFFICIENCY SAVINGS

Since the publication of the Cancer Reform Strategy, the NHS in England has been undergoing a period of fundamental and far-reaching change. The UK economy went into recession in October 2008 and the following May the NHS was set what has been dubbed the 'Nicholson Challenge' (Department of Health 2009). The challenge set was for the NHS to find efficiency savings of £15–20 billion between 2011 and 2015 – the equivalent of 4% per annum. Stephen Dorrell MP, Chair of the Commons Health Select Committee, is quoted as saying that this has never been achieved by any health system anywhere in the world, let alone the NHS (Timmins 2012).

These savings should also be seen in the context of the 2010 Spending Review settlement which gave the NHS 0.4% real-terms growth over the four years to 2014–15. This is a stark comparison to previous years' settlements which had seen year-on-year growth of approximately 6.5% for the decade between 2000–01 and 2009–10 (Harker 2011). At the same time, local authorities have been experiencing significant budget constraints. The Public Spending Review in October 2010 saw £81 billion cut from public spending over four years, including a 7% cut for local councils from April 2011. Provider trusts also face a real-terms decrease in income as the national tariff (Payment by Results) was reduced by 1.5% in 2011–12 (Department of Health 2010). The whole system is therefore coping with the severest financial constraints it has ever faced.

In August 2009, a few months after the Nicholson Challenge was announced, a large-scale service transformation programme – Quality, Innovation, Productivity and Prevention (QIPP) – was introduced to help the NHS deliver the required efficiency savings. This has resulted in numerous projects and programmes being initiated within commissioning and provider

organisations to tackle inefficiencies and increase productivity.

In the wake of these new financial challenges, a new Coalition Government came to power in May 2010 and soon afterwards published its NHS White Paper, *Equity and Excellence: Liberating the NHS* (Secretary of State for Health 2010). The Health Bill finally became law in May 2012 after a two-year period of intense dispute, debate, and negotiation, an unprecedented two month 'pause' in the passage of the bill through Parliament in order to consult further on its contents, and more than 2,000 amendments – though these have been reported as resulting in just 375 substantial changes (Timmins 2012).

The consequent structural and organisational change throughout the NHS is on a scale never before seen. The following is a summary of the main changes, including transitional arrangements where appropriate (see also Appendix 3):

- the establishment of an independent national NHS Commissioning Board which will take responsibility for allocating resources to local commissioners and commission some services (e.g. general practice) directly
- ten SHAs merged into four clusters from October 2011, to cease operation by March 2013 and to be replaced by the NHS Commissioning Board, four regional commissioning sectors and 27 local commissioning board offices (local area teams)
- 152 PCTs clustered into 50 PCTs from December 2010, to cease operation by March 2013, and to be replaced by approximately 212 clinical commissioning groups with local budgeting and commissioning responsibilities
- 45% cut in management costs and 33% cut in administration costs

- the creation of approximately 23 commissioning support units, to provide services and support to CCGs
- 114 NHS Trusts are required to achieve foundation trust status by 2013–14
- the extension of the Any Willing Provider model (re-titled Any Qualified Provider) to a wider range of services
- monitor to become the sector regulator with a duty to promote integrated care and tackle anti-competitive behaviour, a different role from its earlier incarnation in the White Paper as a competition regulator
- transferral of public health functions from PCTs to local government
- the creation of Public Health England, an new executive agency which will incorporate the Health Protection Agency
- establishment of national and local HealthWatch bodies, with the latter replacing Local Involvement Networks as the formal local mechanism for patient and public involvement in NHS services
- the establishment of health and wellbeing boards within local authorities to join up the commissioning of healthcare by GPs with the commissioning of social care and public health improvement
- the establishment of 12 clinical senates, non-statutory advisory bodies of specialists which will input into strategic clinical decision-making and support local commissioning.

In the pre-reform architecture, cancer services had mainly been commissioned by PCTs with some more specialised services being commissioned by NHS Specialised Services. Cancer networks supported the PCT commissioning function by working with both service providers and commissioners to plan and deliver cancer services. This collaborative approach, fostering integration and communication across the whole care, is seen as an essential element of providing high-quality care services.

Improving outcomes: a strategy for cancer provides guidance on the population levels for effective cancer commissioning (Department of Health 2011a). It states that:

*A significant amount of cancer care is best commissioned for populations covering 1½–2 million. This includes specialist surgical services for upper gastrointestinal, urological, gynaecological, head and neck cancers and chemotherapy and radiotherapy. Where population size requirements mean that a*

*single GP consortium (now CCG) is too small to commission a particular service, then GP consortia will wish to work collaboratively. GP consortia will be able to decide whether they wish to identify a lead consortium for commissioning more specialised cancer services (outside of NHS Commissioning Board commissioning) or to do so through commissioning support organisations.*

(DEPARTMENT OF HEALTH 2011A: 71)

According to figures released by the Department of Health in 2011, the average population covered by a pathfinder consortium (forerunner of a CCG) was just over 202,000.

This indicates that collaboration between CCGs will be essential for some services. It also suggests the need for local coordination and leadership to ensure a collaborative approach is achieved – a role that, up until now, cancer networks have typically (although not exclusively) fulfilled. A National Audit Office survey of PCTs, carried out in 2010, found that ‘99% of PCTs believe they work well with their cancer network in the delivery of cancer services, with 88% using the advice of cancer networks on service improvement and design and 83% on planning and prioritisation’ (cited by The Cancer Campaigning Group 2011: 4).

The Government gave a commitment last May to fund cancer networks until 2013 and, in the longer term, that clinical networks per se would be strengthened and embedded and supported by the NHS Commissioning Board. There is still some lack of clarity, however, over the exact configuration of networks, though it is now accepted that there will be far fewer than the current 28, with less staff and smaller budgets. Clinical senates, established in 12 geographical areas, will support new ‘strategic clinical networks’ which will be required to cover defined areas of healthcare: cancer, cardiovascular disease, maternity and children, and mental health, dementia and neurological conditions. It appears it will be left to local area teams to determine the exact number and composition of these networks, taking into account patient flows.

Some experts have warned that the reforms are too far reaching and are happening too quickly, particularly given the financial challenges faced by the NHS (The King’s Fund 2011; NHS Confederation 2011). A recent briefing from The Nuffield Trust reminds observers of the loss of financial control that occurred during the major

reorganisation of commissioning and performance management structure in 2005 and 2006, which was a time of significant additional investment in the NHS (Smith and Charlesworth 2011). It goes on to discuss the international evidence on mergers and large-scale reorganisations, which highlights the risk of losing financial grip during times of major change.

On the issue of transition, the NHS Confederation has remarked that:

*There will be significant risks during the transition to the new system. These include the possible loss of grip on money and quality during the process of change, as well as the loss of skilled commissioning staff from PCTs.*

(NHS CONFEDERATION 2011: 7)

Surveys of public opinion point to another potential source of risk. For example, in a recent national population survey of attitudes towards the NHS, 67% of respondents reported knowing nothing or very little about the changes being made to the health service. Despite – or perhaps because of – this uncertainty about the reforms, more than two in five respondents (43%) thought that the changes being made to the NHS would make services worse for patients (Ipsos MORI 2012).

Perhaps the most troubling commentary, however, comes from the NHS Chief Executive, Sir David Nicolson. Speaking at a conference held by the Royal College of General Practitioners in October 2012, he warned that ‘big, high-profile, politically driven objectives and changes like this almost always end in misery and failure’ (Boffey 2012).

# RECENT TRENDS IN CANCER SERVICE PERFORMANCE AND EXPENDITURE

This chapter examines trends in performance for the 2010–11 and 2011–12 financial years, covering the period during which the health reforms were introduced, the Health and Social Care Act passed through Parliament and local implementation commenced. The chapter also includes an analysis of recent NHS expenditure on cancer services – using Department of Health programme budget data.

## SUMMARY

1. Access to diagnostics has been variable, with significant increases in the number of patients waiting more than six weeks for a diagnostic test during 2010 and 2011. Waits have subsequently returned to previously seen levels for radiological imaging tests, but have yet to do so for endoscopic tests.
2. Although the number of patients referred by their GP with suspected cancer has risen substantially in recent years, services have continued to perform well against the 2 week, 31 day and 62 day targets.
3. Over much of the 2000s, real-terms expenditure on cancer services grew year-on-year. In the 2008–9 financial year alone, expenditure increased by 11.2%. But the most recent data we analysed showed a reversal of this trend, with a real-terms spending decrease of 2.6% overall and 3.4% per capita in 2010–11.

## NATIONAL CANCER WAITING TIMES STANDARDS

The performance of NHS cancer services against a number of national waiting times standards is routinely monitored and reported including:

### 14 day wait from urgent referral to first appointment

Standard: 93% of urgent referral patients should be seen by a specialist within 14 days of a referral from a GP.

### 62 day wait from urgent referral to first treatment

Standard: 85% of patients should wait no longer than 62 days between an urgent referral and first treatment.

### 31 day wait from diagnosis to first treatment

Standard: 96% of patients should wait no longer than 31 days between being diagnosed with cancer and having their first treatment.

### 31 day wait for second or subsequent treatment

Standards:

- 98% of patients should wait no longer than 31 days between a first treatment and their second (for drug treatments)
- 94% of patients should wait no longer than 31 days between a first treatment and their second (for surgical treatments)

## CANCER WAITING TIMES

The urgent (two week) referral pathway was introduced by the Department of Health in 2000 to address the issue of extended waiting times for patients with suspected cancer. The NHS operational standard specifies that 93% of patients urgently referred by their GP should be seen by a specialist within 14 days. Data published by The Royal College of General Practitioners in 2011 found that approximately 54% of patients diagnosed with cancer were originally referred on the two week wait (Table 1). As this highlights, while urgent referral times are an important indicator of performance, they do not cover all cancer patients.

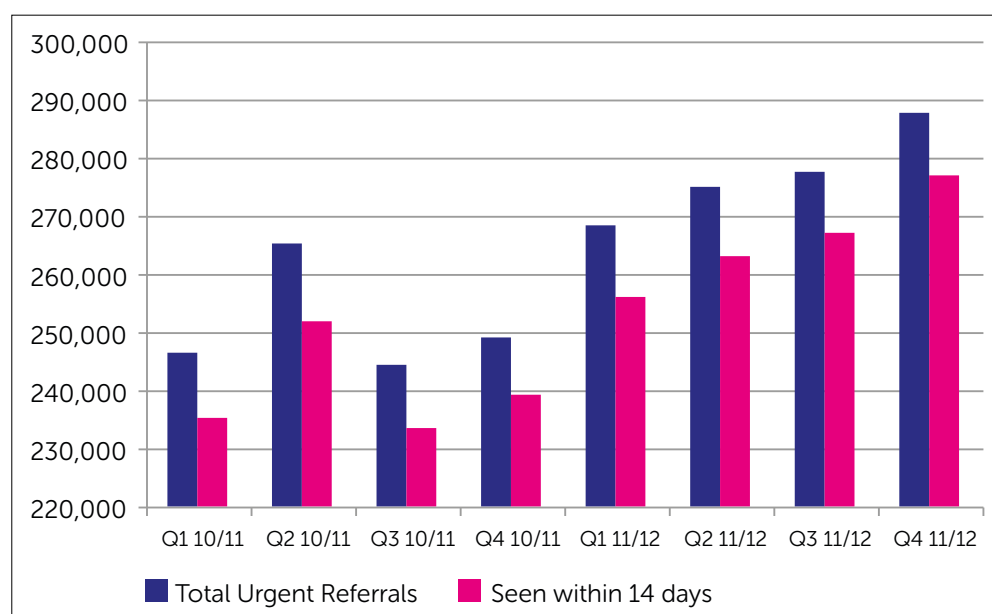
**Table 1. Routes to diagnosis**

	Emergency*	2 week	Routine	Private	Not referred by practice	Unknown	Total	Number of patients
Total	12.90%	53.90%	14.80%	4.90%	7.00%	6.50%	100%	18,879

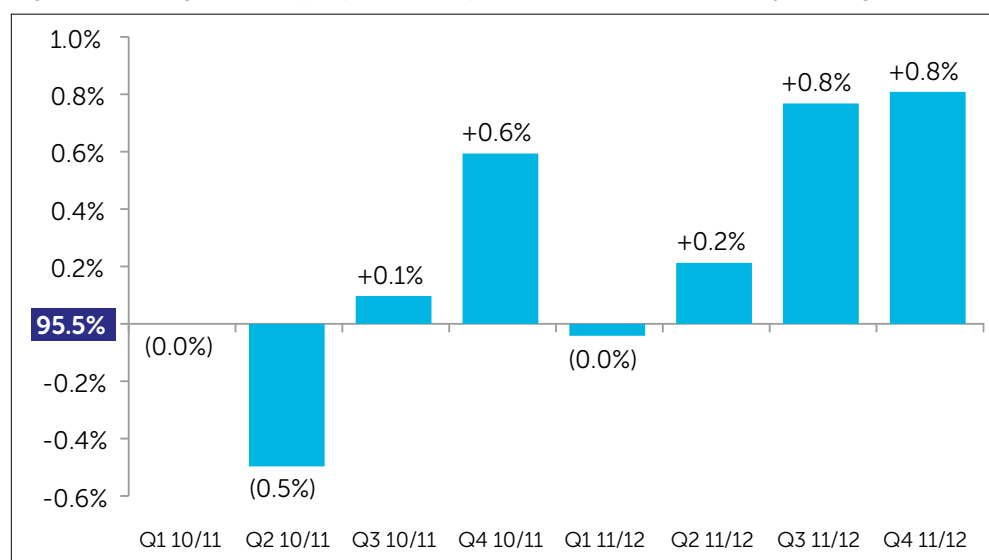
SOURCE: ROYAL COLLEGE OF GENERAL PRACTITIONERS 2011

The number of patients urgently referred for suspected cancer increased substantially over the 2010–11 and 2011–12 financial years. Urgent referrals per quarter rose by 16.7%, from 246,000 in quarter 1 (Q1) of 2010–11 to 287,000 in quarter 4 (Q4) of 2011–12. A year-on-year comparison shows a 10.3% increase, with 1 million urgent referrals in 2010–11 and 1.1 million in 2011–12. When calculated by weighted population, this represents a real growth in urgent referrals of 9.4%.

As Figure 1 illustrates, at the same time that demand for cancer services has increased, the proportion of patients being seen within 14 days has improved. In Q1 2010–11, 95.5% of patients urgently referred by their GP were seen by a specialist within 14 days. This quarterly figure increased by 0.8% to 96.3% in Q4 2011–12.

**Figure 1. Urgent referrals per quarter and number seen within 14 days**

Within this positive overall trend, some fluctuations in performance can be seen. Notably, the proportion of patients seen within the 14 day target dipped by 0.5% in Q2 2010–11, after which a more general upward pattern can be seen (Figure 2). Despite this fluctuation, over the period reviewed, services consistently exceeded the operational standard of 93%.

**Figure 2. Changes in the proportion of patients seen within 14 days of urgent referral**

These overall figures do mask some variation in performance against the two week target by type of cancer (Table 2). In 2011–12, the proportion of patients seen within two weeks ranged from 98.6% for acute leukaemia to 94.3% for upper gastrointestinal cancer. For most cancers performance has improved in line with national trends, but not for all. Marginal declines in performance were reported for brain/CNS, haematological malignancies and sarcoma, with a slightly larger decrease (1.2%) for 'other cancers'.

**Table 2. Urgent referrals seen within 14 days by cancer type**

Sum of within 14 days	Seen within 14 days		% of total URS		Change
Suspected cancer type	10/11	11/12	2010/11	2011/12	
Acute leukaemia (AL)	227	217	97.4%	98.6%	1.2%
Brain/central nervous system tumours	4,716	5,616	97.1%	97.0%	-0.2%
Breast cancer	202,228	202,801	96.8%	97.6%	0.8%
Children's cancer	4,738	5,215	95.8%	96.2%	0.3%
Gynaecological Cancer	87,477	100,457	96.0%	96.0%	0.0%
Haematological Malignancies (Exc. AL)	8,151	8,946	97.5%	97.2%	-0.3%
Head and neck cancer	82,674	95,232	96.3%	96.4%	0.1%
Lower Gastrointestinal Cancer	147,728	177,164	94.7%	94.7%	0.1%
Lung cancer	38,254	42,447	97.6%	97.7%	0.0%
Other cancer	2,334	1,845	97.1%	95.9%	-1.2%
Sarcoma	3,919	4,539	96.9%	96.6%	-0.2%
Skin cancer	169,306	186,453	94.4%	95.5%	1.1%
Testicular Cancer (Tc)	6,690	6,935	97.6%	98.2%	0.6%
Upper Gastrointestinal Cancer	96,773	107,315	93.8%	94.3%	0.5%
Urological Malignancies (Exc Tc)	104,522	117,852	95.3%	95.5%	0.1%
<b>Grand Total</b>	<b>959,737</b>	<b>1,063,034</b>	<b>95.5%</b>	<b>95.9%</b>	<b>0.4%</b>

The number of patients subsequently diagnosed with and treated for cancer has also increased, from 105,034 in 2010–11 to 113,178 in 2011–12 (Table 3). When weighted by population, this represents a 6.8% real growth in cancer treatment. As with two week referrals, this increase in demand does not appear to have had a negative impact on patient access as waiting time performance has also slightly improved (0.3%). By Q4 2011–12, 87.3% of patients were treated within 62 days of the initial referral being made.

**Table 3. Urgent referrals first treated within 62 days and after 62 days**

Year	Treated within 62 days	Year on Year Growth	% of Total	Treated After 62 days	Year on Year Growth	% of Total	Total Treated	Year on Year Growth	Treated Per 100 Persons
2010/11	91,415		87.0%	13,619		13.0%	105,034		0.204
2011/12	98,794	8.1%	87.3%	14,384	5.6%	12.7%	113,178	7.8%	0.218
<b>Real Growth</b>									<b>6.80%</b>

Table 4 reveals the lack of any discernible quarter-on-quarter pattern in the data. However, it does show that approximately 32% of urgently referred patients received their first treatment within 31 days of the referral and approximately 25% had their first treatment towards the end of the maximum 62 day wait period.

**Table 4. Urgent referrals first treated by quarter**

Year	Quarter	Within 31 Days	32 to 38 Days	39 to 48 Days	49 to 62 Days	63 to 76 Days	77 TO 90 Days	91 to 104 Days	104 + Days	Total Treated
10/11	Q1_10/11	8,225	3,225	4,410	6,532	1,116	883	530	669	25,590
	Q2_10/11	8,823	3,360	4,708	7,133	1,274	995	529	766	27,587
	Q3_10/11	8,382	3,214	4,500	6,598	1,155	876	530	768	26,023
	Q4_10/11	8,529	3,207	4,225	6,345	1,165	939	562	862	25,834
<b>10/11 Total</b>		<b>33,959</b>	<b>13,006</b>	<b>17,843</b>	<b>26,608</b>	<b>4,710</b>	<b>3,693</b>	<b>2,151</b>	<b>3,065</b>	<b>105,034</b>
11/12	Q1_11/12	8,671	3,461	4,614	7,144	1,350	1,010	559	766	27,574
	Q2_11/12	9,409	3,607	4,737	7,486	1,199	924	626	914	28,902
	Q3_11/12	9,256	3,599	4,915	7,257	1,145	934	562	799	28,467
	Q4-11/12	9,062	3,481	4,701	7,396	1,211	962	563	860	28,235
<b>11/12 Total</b>		<b>36,398</b>	<b>14,148</b>	<b>18,967</b>	<b>29,283</b>	<b>4,905</b>	<b>3,830</b>	<b>2,310</b>	<b>3,339</b>	<b>113,178</b>
<b>Grand Total</b>		<b>70,357</b>	<b>27,153</b>	<b>36,810</b>	<b>55,890</b>	<b>9,615</b>	<b>7,523</b>	<b>4,461</b>	<b>6,404</b>	<b>218,211</b>

So far we have focused on waiting times for patients entering secondary care via the urgent referral route. When looking at all patients treated for cancer – which includes all routes to diagnosis – similar trends are found. The total number of patients treated for cancer increased by 3.4% (weighted per 100 population) between 2010–11 and 2011–12. Services appeared to cope with this increase, maintaining the proportion of patients receiving their first treatment within 31 days from diagnosis at 98.4% (Table 5). The proportion of patients receiving a second treatment within 31 days of their first improved marginally from 98.6% to 98.8% (Table 6).

**Table 5. Patients treated for cancer and proportion treated within 31 days of diagnosis**

Year	Total patients treated	Total patients treated per 100 of pop	Patients treated within 31 days of diagnosis	Percentage of patients treated within 31 days
10/11	244,630	0.47	240,627	98.4%
11/12	255,202	0.49	251,169	98.4%
<b>Growth</b>	<b>4.3%</b>	<b>3.4%</b>		

**Table 6. Patients waiting no longer than 31 days between first and second treatment**

Year	Total patients treated	Total treated per 100 persons	Patients treated within 31 days	Percentage of total treated
10/11	125,583	0.24	123,808	98.6%
11/12	134,981	0.26	133,383	98.8%
Growth	7.5%	6.6%		

**DIAGNOSTIC TESTS WAITING TIMES**

Given the data presented above, it will come as no surprise that there has also been a substantial increase in the number of diagnostic tests performed. As Table 7 shows, more than 800,000 additional tests were undertaken in 2011–12, a 5.5% increase on the 2010–11 figure. This followed an increase in the previous year of 4.9%.

**Table 7. Diagnostic tests performed and proportional split**

	Total Diagnostic Tests Performed			Proportion of the total tests performed		
	09/10	10/11	11/12	09/10	10/11	11/12
MRI	1,895,842	2,035,440	2,192,511	13.2%	13.5%	13.8%
CT	3,113,470	3,339,342	3,614,539	21.7%	22.2%	22.8%
Non-obstetric ultrasound	5,073,625	5,353,578	5,592,035	35.3%	35.6%	35.2%
Barium Enema	107,775	83,475	68,550	0.8%	0.6%	0.4%
DEXA Scan	309,456	310,733	319,597	2.2%	2.1%	2.0%
Audiology	1,184,204	1,213,293	1,230,460	8.2%	8.1%	7.8%
Cardiology – echocardiography	965,094	994,334	1,052,974	6.7%	6.6%	6.6%
Cardiology – electrophysiology	18,830	20,474	24,483	0.1%	0.1%	0.2%
Neurophysiology	174,586	173,262	174,246	1.2%	1.2%	1.1%
Respiratory physiology	86,260	94,171	95,196	0.6%	0.6%	0.6%
Urodynamics – pressures and flows	91,252	89,055	87,220	0.6%	0.6%	0.5%
Colonoscopy	315,657	324,429	360,443	2.2%	2.2%	2.3%
Flexi sigmoidoscopy	197,342	200,462	217,767	1.4%	1.3%	1.4%
Cystoscopy	305,312	306,910	312,422	2.1%	2.0%	2.0%
Gastroscopy	515,509	513,416	531,909	3.6%	3.4%	3.4%
	14,354,214	15,052,374	15,874,352	100.0%	100.0%	100.0%
Annual Growth		4.9%	5.5%			

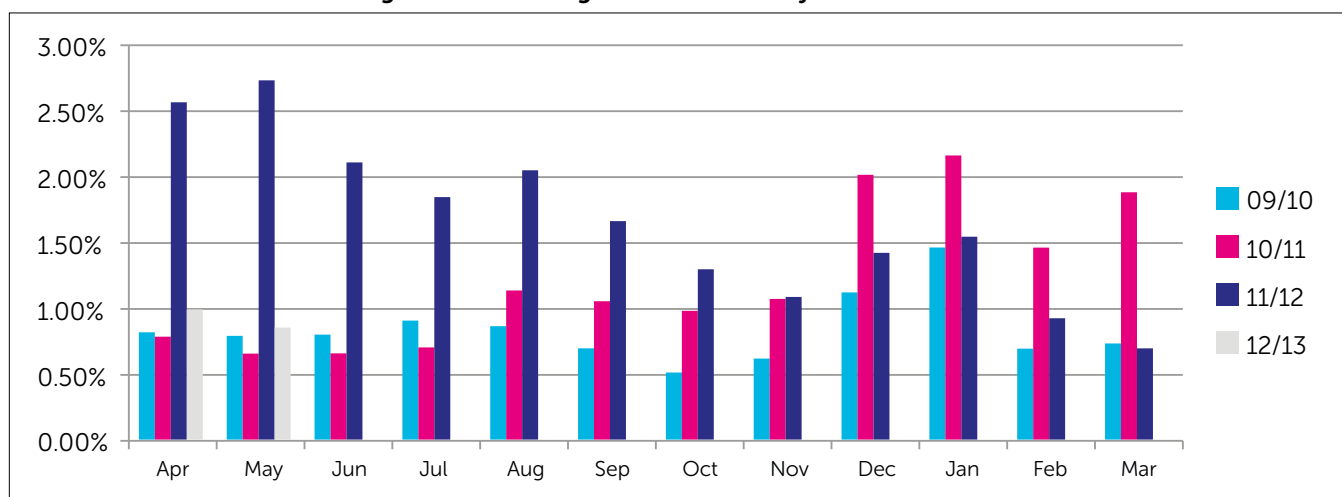
The table also includes information on the proportional split of total tests by investigation type, which has remained relatively stable over the time period reviewed. In 2010–11, radiological imaging tests (MRI, CT and non-obstetric ultrasound) accounted for 71.8% of all tests performed. The second most common category was endoscopic tests (colonoscopy, flexisigmoidoscopy, cystoscopy and gastroscopy), which accounted for just under one in ten (9.1%) of all tests performed.

Table 8 shows the average monthly waiting list size, which has increased by approximately 9% per year from 2009–10. It also reports the average number of patients waiting more than six weeks for a test, which rose from 0.8% in 2009–10 to 1.6% in 2011–12. However, interpretation of this is difficult as the figures are very small relative to the overall size of the waiting list.

**Table 8. Average waiting list size and patients waiting more than 6 weeks**

	2009/10	2010/11	2011/12
Average Waiting list	492,205	537,114	585,656
Average >6 weeks wait	4,073	6,484	9,618
6 Week % of waiting list	0.8%	1.2%	1.6%

Throughout 2009–10 the proportion of patients waiting more than 6 weeks remained below 1%, except for the winter period when figures peaked before returning to previously seen levels (Figure 3). The 2010–11 year showed a similar pattern until December 2010, when the proportion of longer waits rose sharply and reached 2%. Levels remained high for the first half of 2011, peaking at over 2.5% in May of that year. They did not return to below 1% until February 2012, but the service has maintained this lower level since then.

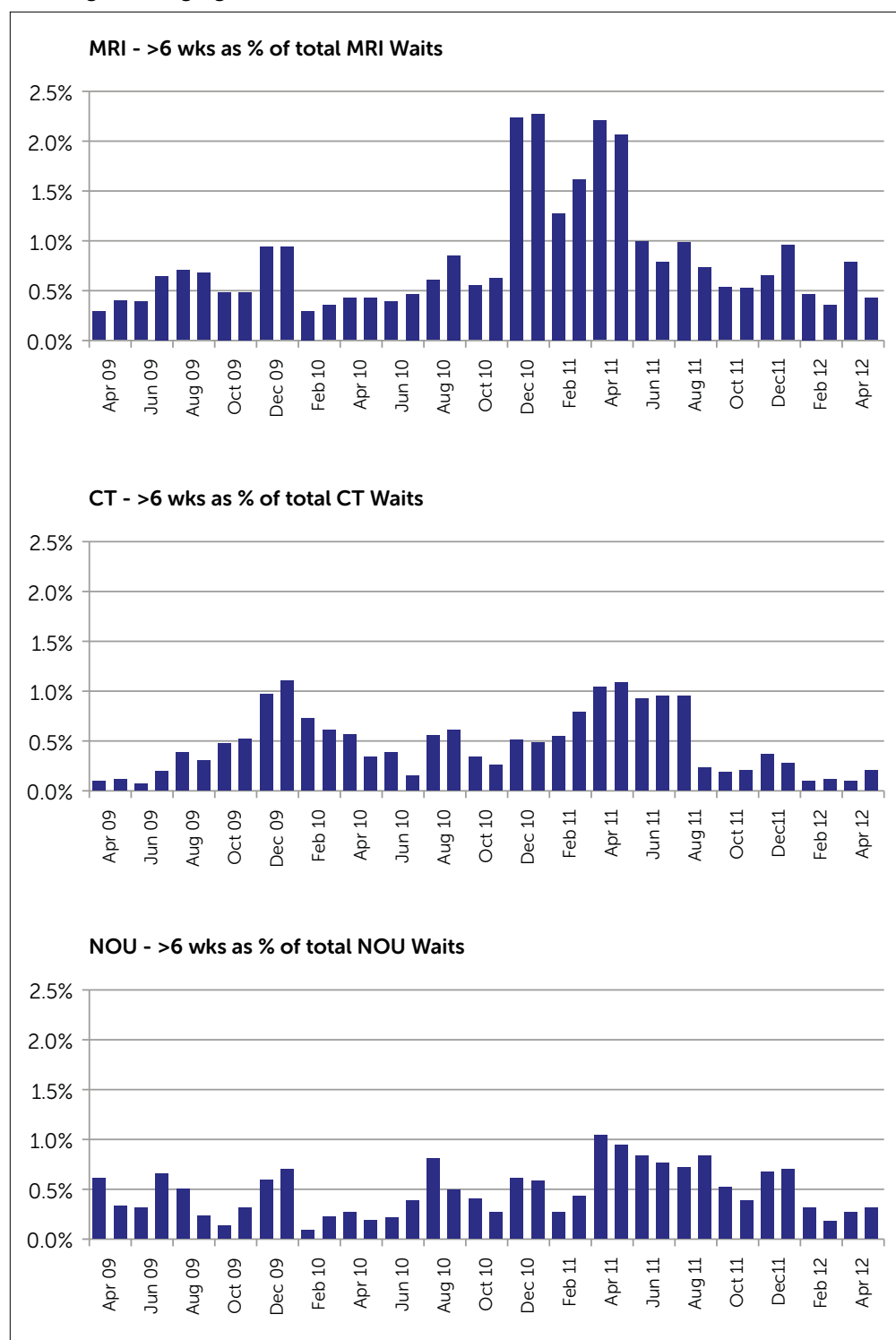
**Figure 3: Waits longer than 6 weeks by month**

Patient waits for individual diagnostic tests present similar patterns in terms of increases in both number of tests performed and proportion of patients waiting longer than 6 weeks. In the case of radiological imaging tests, the waiting time performance for MRI tests slipped in 2010–11 while that of CT and non-obstetric ultrasound declined in 2011–12 (Table 9).

**Table 9. Average waiting lists and average 6+ week waits by year (radiological imaging tests)**

Year	Average of Magnetic Resonance Imaging Total Wait	Average of Magnetic Resonance Imaging >6wk	Average of Magnetic Resonance Imaging %	Average of Computer Tomography Total Wait	Average of Computer Tomography >6wk	Average of Computer Tomography %	Average of Non-obstetric ultrasound Total Wait	Average of Non-obstetric ultrasound >6wk	Average of Non-obstetric ultrasound %
09/10	89,835	469	0.5%	54,272	278	0.5%	167,880	610	0.4%
10/11	99,031	945	0.9%	59,264	298	0.5%	186,437	717	0.4%
11/12	109,841	974	0.9%	66,986	378	0.6%	207,626	1,299	0.6%

**Figure 4. Proportion of patients waiting more than 6 weeks for radiological imaging tests**



Analysis of waiting times per month provides a more detailed picture. Figure 4 shows peaks in waiting times for all three radiological imaging tests at various points during the period reviewed, but in all cases there was a return to normal levels by early 2012.

The number of patients receiving endoscopic tests is relatively small, but increases in waiting times have been more marked. Each displays a gradual decline in waiting time performance, with the proportion of waits greater than 6 weeks rising each year (Table 10). The increase in the number of patients waiting more than 6 weeks is disproportional to the increase in the total waiting list size.

**Table 10. Average waiting lists and average 6+ week waits by year (endoscopic tests)**

Year	Avg of Colon'y Total Wait	Avg of Colon'y >6wk	Avg of Colon'y %	Avg of Flexi'y Total Wait	Avg of Flexi'y >6wk	Avg of Flexi'y %	Avg of Cyst'y Total Wait	Avg of Cyst'y >6wk	Avg of Cyst'y %	Avg of Gastr'y Total Wait	Avg of Gastr'y >6wk	Avg of Gastr'y %
09/10	21,949	433	2.0%	12,543	203	1.6%	11,751	246	2.1%	29,229	494	1.7%
10/11	24,710	843	3.4%	13,755	365	2.6%	12,162	299	2.5%	30,685	774	2.5%
11/12	27,200	1,533	5.7%	15,346	793	5.2%	12,749	483	3.8%	31,435	1,236	3.9%
Growth 10/11-11/12	10%	82%		12%	117%		5%	61%		2%	60%	

The month-by-month picture shows that a significantly higher proportion of patients had to wait more than 6 weeks for endoscopic tests. For all four types of test, waits started to increase from summer 2010 and peaked in May 2011. Although waiting times are now beginning to recover, this recovery has yet to achieve the pre-summer 2010 level (Figure 5).

**Figure 5. Proportion of patients waiting more than 6 weeks for radiological imaging tests**

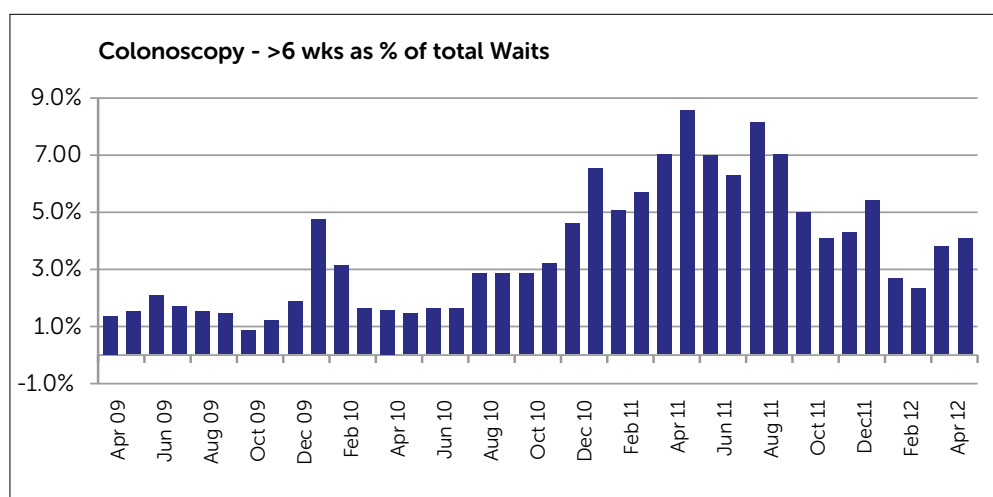
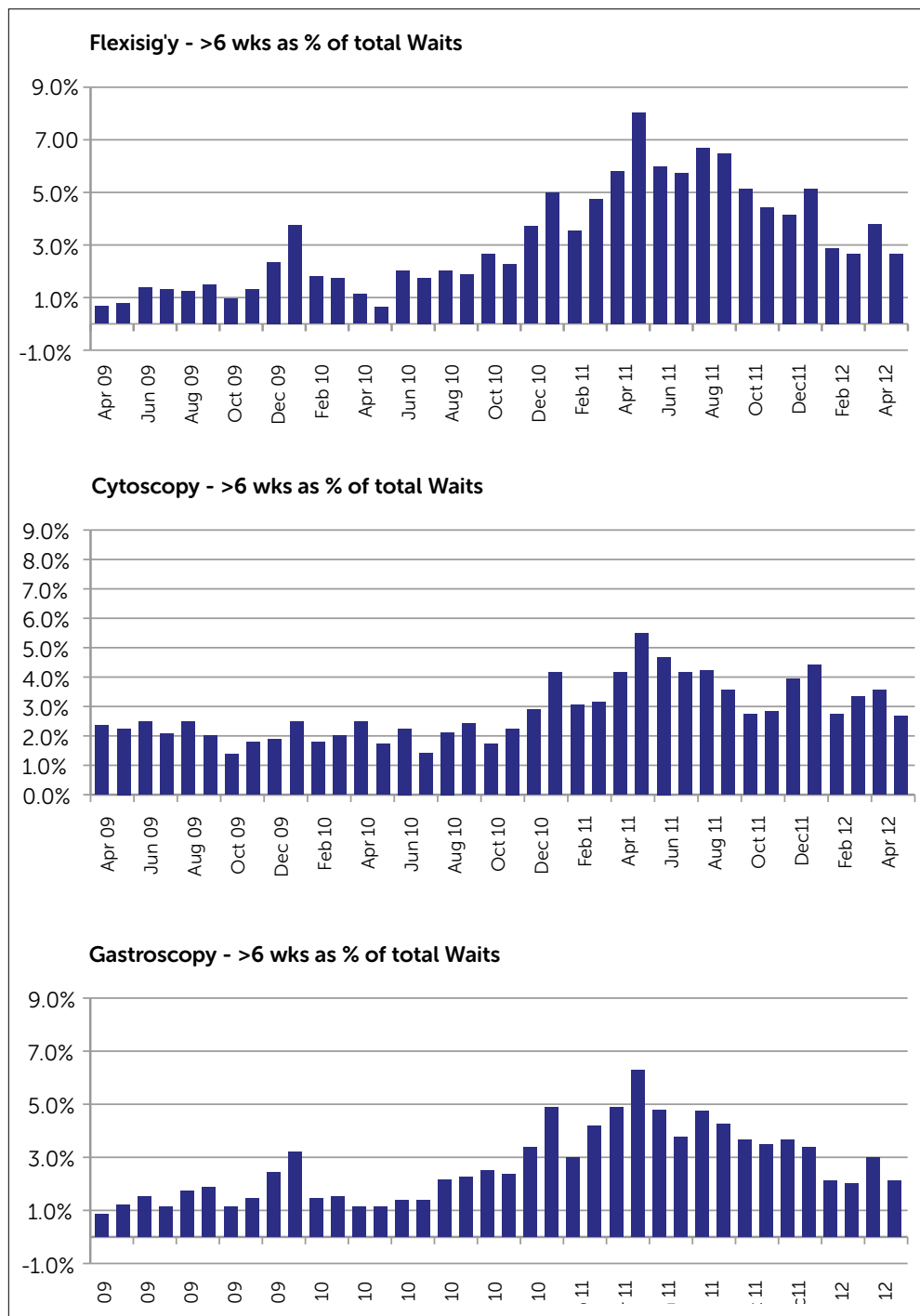
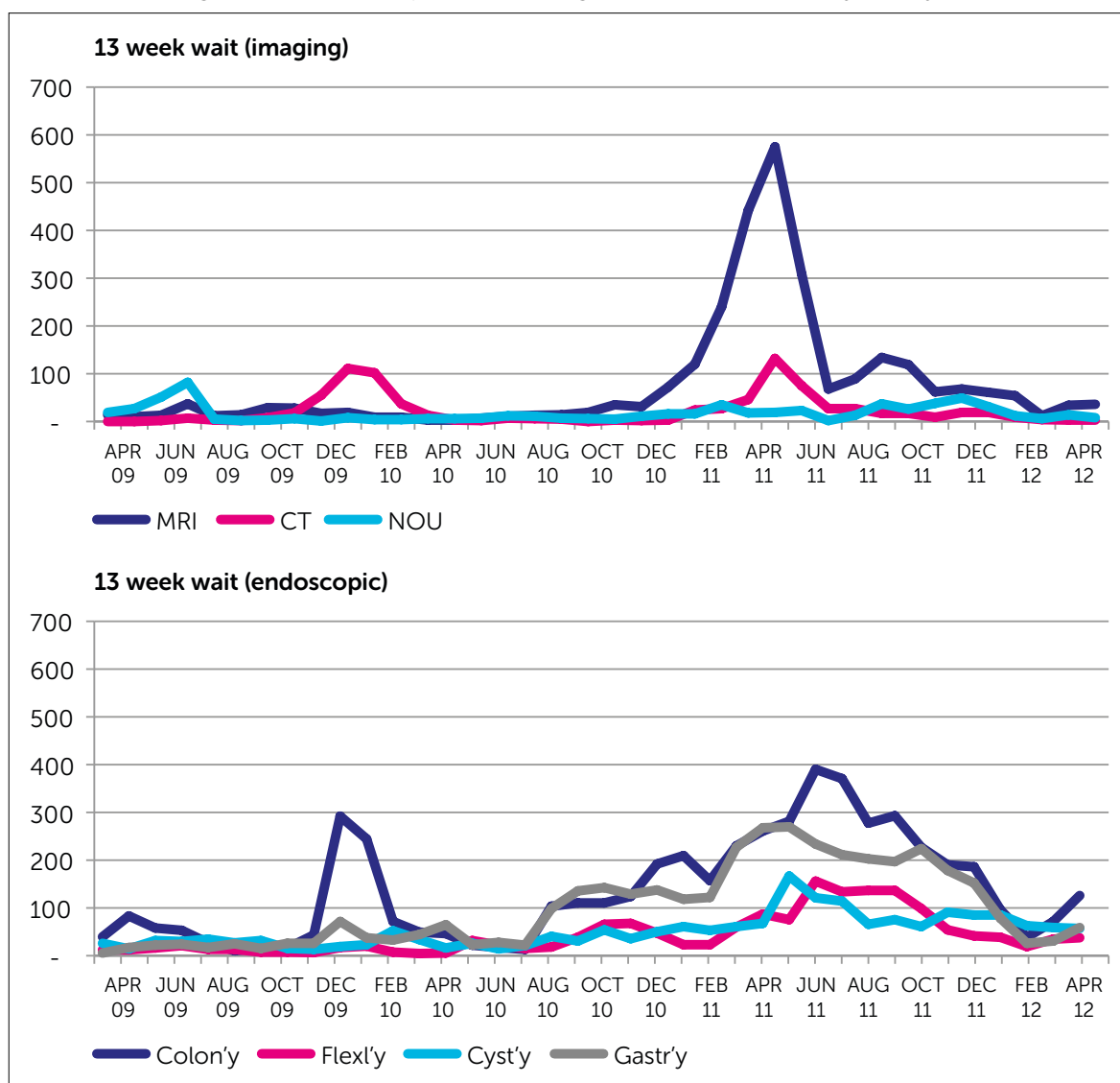


Figure 5. (continued)



The data also provide a view of the number of patients waiting longer than 13 weeks for tests. The numbers are generally very small (i.e. fewer than 100 patients). However – as Figure 6 describes – movements in the proportion of 6 week waits are also reflected in the 13 plus week wait. In particular, the same significant rise from summer 2010 and slow recovery into 2012 are illustrated for the endoscopic tests.

Figure 6. Number of patients waiting more than 13 weeks by test by month



### EXPENDITURE ON CANCER SERVICES

Since 2003, the Department of Health has collected expenditure data categorised by clinical speciality or health area programme budgeting. In order to improve the quality of the data, continual refinements have been made making year-on-year comparisons very difficult. For this reason the analysis, for the most part, is at the aggregate level. Calculation of programme budgeting expenditure data is complex and relies on assimilation of activity and cost data from a range of sources. As such, the figures within this report should be viewed as best estimates rather than definitive values.

Data show that a total of £20.6 billion was spent on cancer services over the four years between 2007–08 and 2010–11 (Table 1). Over this period, cancer received an average of 6.2% of the overall NHS spend. Excluding expenditure coded as 'miscellaneous', cancer is the fourth highest area of NHS spending after mental health, primary medical care (GSM/ PMS) and circulatory diseases.

**Table 1: Top five areas of NHS expenditure**

Year	Mental Health			GMS/PMS			Circulation			Miscellaneous			Cancers and tumours		
	Spend £bn	% of Total Spend	Rank of spend	Spend £bn	% of Total Spend	Rank of spend	Spend £bn	% of Total Spend	Rank of spend	Spend £bn	% of Total Spend	Rank of spend	Spend £bn	% of Total Spend	Rank of spend
2007/08	9.17	12.5%	1	7.48	10.2%	2	6.33	8.6%	3	4.27	5.8%	5	4,573	6.2%	4
2008/09	9.79	12.5%	1	7.44	9.5%	2	6.66	8.5%	3	4.21	5.4%	5	4,843	6.2%	4
2009/10	10.61	12.1%	1	7.65	8.8%	2	7.17	8.2%	3	5.05	5.8%	5	5,566	6.4%	4
2010/11	10.94	11.9%	1	7.63	8.3%	3	6.99	7.6%	4	8.06	8.8%	2	5,638	6.1%	5
<b>Grand Total</b>	<b>40.52</b>	<b>12.2%</b>		<b>30.20</b>	<b>9.1%</b>		<b>27.14</b>	<b>8.2%</b>		<b>21.59</b>	<b>6.5%</b>		<b>20,621</b>	<b>6.2%</b>	

Table 2 shows trends in real-terms cancer expenditure over the same four-year period. Between 2007 and 2010 cancer spending saw strong growth, with a significant boost (11.2%) in expenditure in the 2009–10 financial year. But this trend reversed in 2010–11. Due to a combination of low nominal growth in total expenditure, a small reduction in the proportion of the NHS budget allocated to cancer and high inflation there was a real-terms decline in spending of 2.6%. When calculated as average expenditure per capita, this decline in spending reaches 3.4% (Table 3).

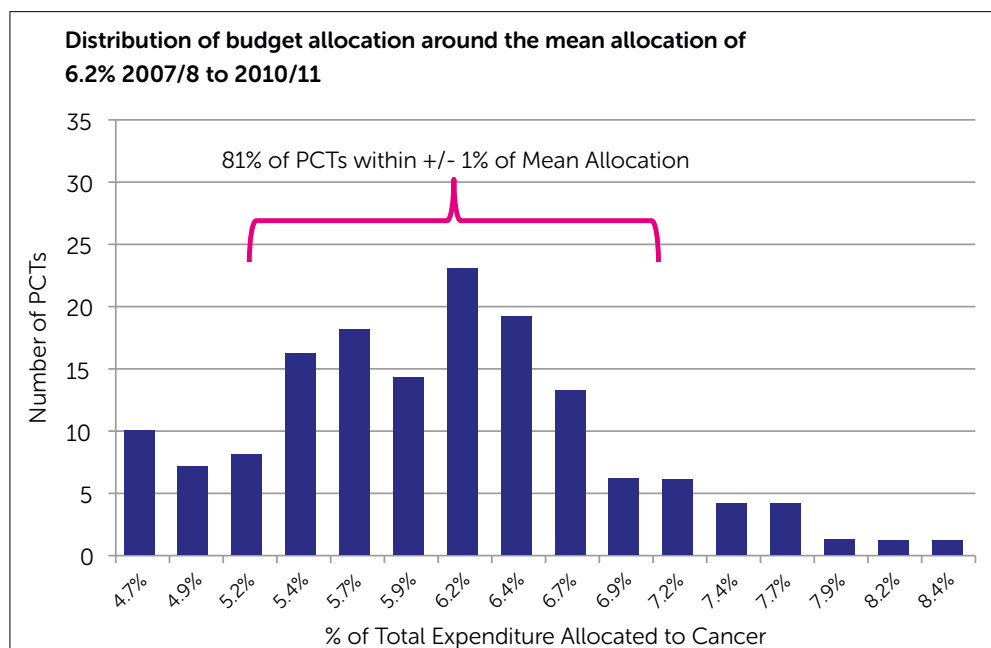
**Table 2: Annual NHS cancer spend**

Year	Cancers and tumours	% of Total Spend	Rank of spend	Growth in cancer spend	Spend at 2010/11 prices	Real Growth
	Spend £bn			Nominal Growth		
2007/08	4,573	6.2%	4	10.9%	5,061	
2008/09	4,843	6.2%	4	5.9%	5,208	2.9%
2009/10	5,566	6.4%	4	14.9%	5,789	11.2%
2010/11	5,638	6.1%	5	1.3%	5,638	-2.6%
<b>Grand Total</b>	<b>20,621</b>	<b>6.2%</b>				

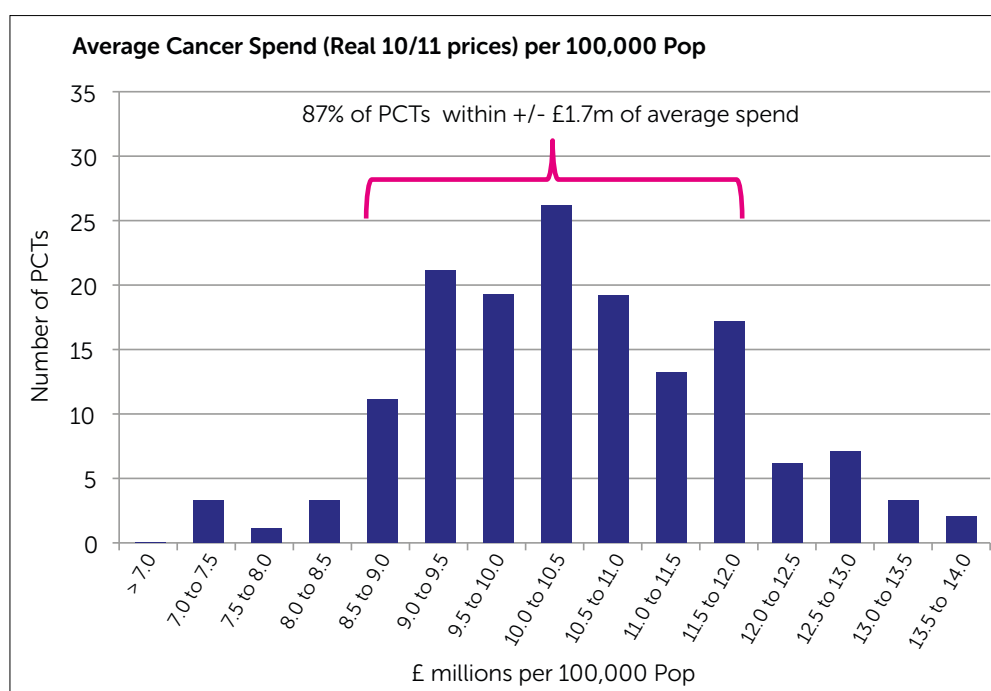
**Table 3: Real growth / decline in cancer spend per head of population**

Year	Unified Weighted POP	Total Cancer Spend (Nominal)	Cancer Spend per 100,000 of POP (Nominal)	Total Cancer Spend 2010/11 Prices	Cancer Spend per 100,000 of POP 2010/11 Prices	Growth in Spend per Head of POP 2010/11 Prices
	millions	£ millions	£ millions	£ millions	£ millions	
2007/08	50.70	4,573	9.0	5,061	10.0	7.8%
2008/09	51.22	4,843	9.5	5,208	10.2	1.9%
2009/10	51.96	5,566	10.7	5,789	11.1	9.6%
2010/11	52.37	5,638	10.8	5,638	10.8	-3.4%
<b>Average / Total</b>	<b>51.56</b>	<b>20,621</b>				

The proportion of local budgets allocated to cancer broadly mirrors the national picture. Against a national average allocation of 6.2%, 123 PCTs (81%) allocated between 5.2% and 7.2% of their expenditure to cancer services (Figure 7).

**Figure 7: Individual PCT's allocation to cancer services**

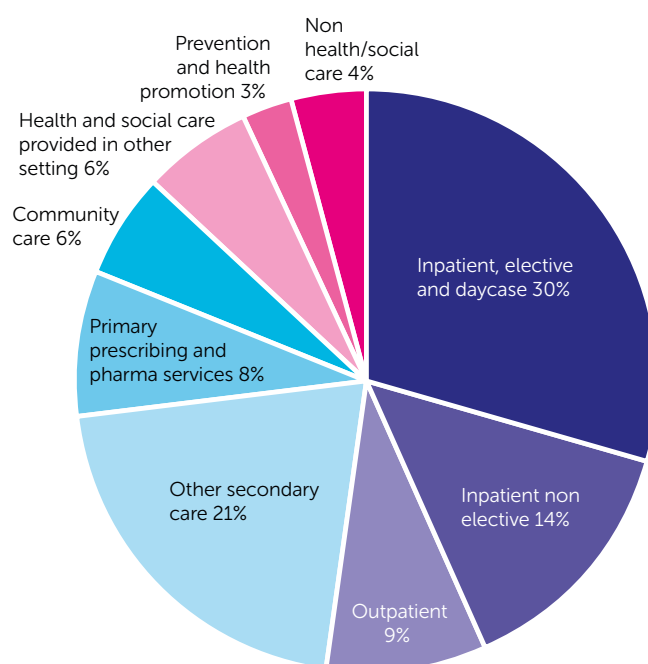
Within individual PCTs the proportion of their total budget allocated to cancer services changes annually and there are some instances where single year allocations rise or fall significantly. By converting nominal cancer spend figures to 2010–11 prices, the average spend per 100,000 of population across the four years was £10.3 million, with 87% of PCTs within a range of +/- £1.7 million (Figure 2).

**Figure 8: Range of 4 year average cancer spend per 100,000 population**

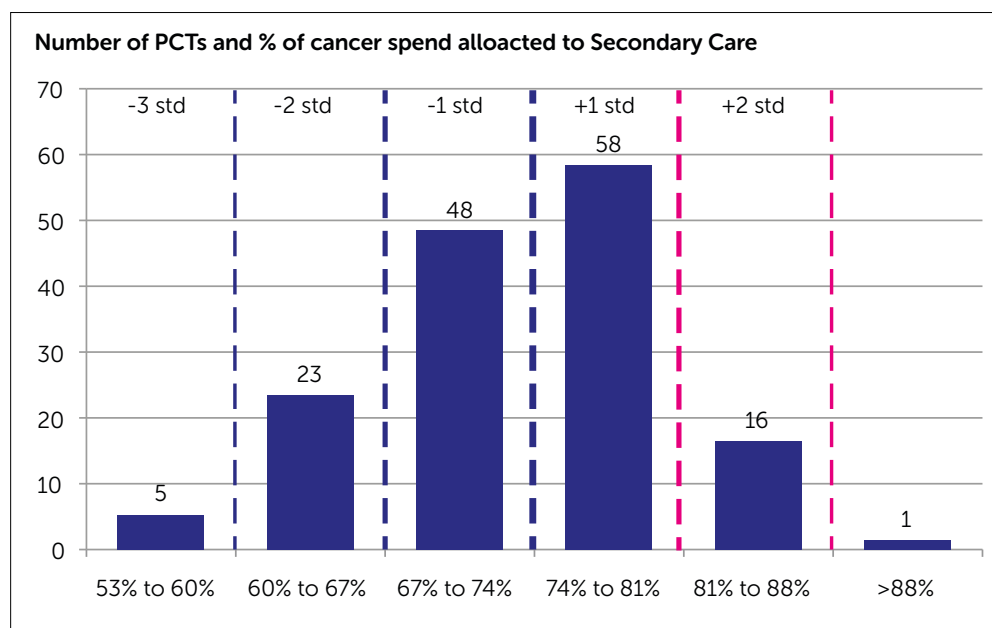
A new development in the 2010–11 programme budget data was the additional coding of spend by care setting. As would be expected, the data reveal that the majority of cancer expenditure (around 74%) is on secondary care services. Of the remainder, 8% was in primary prescribing, 6% in the community, 6% in other care settings such as nursing homes and hospices, 3% on prevention and promotion and 4% on overheads.

Data at individual PCT level shows significant variation in allocation across the care settings. For example, the proportion of total cancer spend allocated to secondary care is on average 74% but ranges from 53% to just over 88%. While the majority of PCTs are within +/- 7% (one standard deviation) of the average, around 30% of PCTs fall outside this range.

**Figure 9: Allocation of cancer spend by care setting 2010–11**



**Figure 10: Range of PCT proportional budget allocation to secondary care**



# SUMMARY OF THE INTERVIEW FINDINGS

Views and experiences of the NHS reforms and efficiency savings were explored through interviews with cancer experts at a national level and in eight selected case study cancer networks. A total of 52 people took part in either a face-to-face or telephone interview between April and August 2012.

In the expectation that interviews would cover sensitive issues, and to encourage the free expression of views, anonymity was guaranteed. Therefore, quotations from the interviews have been attributed using only the interviewee's role. Further details about the research methodology can be found in the Appendix.

## SUMMARY

### 1. Scale of change

There was a widespread view that the current changes to the NHS are of a different order and scale than previously seen. The sheer scale of the reforms, with changes being implemented and felt at the local, regional and national level across commissioning, provision and public health, was cited as a reason.

### 2. Financial austerity

The NHS has periodically implemented government reforms or made financial savings but it has never before been asked to achieve these at the same time. Meeting the target of finding £20 billion in productivity improvements would require large-scale service redesign, not just the identification of 'quick wins'. There was a widespread sense that the capacity and skills to undertake this kind of work was being jeopardised by the disruption which the reforms had created locally.

### 3. Fragmentation

Interviewees felt that the reforms were starting to cause fragmentation of cancer services, in relation to both commissioning and provision. The scale of change, combined with ongoing uncertainty about key aspects of the reform programme and financial pressures, had disrupted local arrangements, relationships and service development work. While cancer funding has been relatively protected, services such as clinical nurse specialists and rehabilitative and support services appear to be soft targets for cost savings.

### 4. Cancer knowledge and expertise

The importance of CCGs having access to cancer knowledge and expertise was frequently emphasised, and this was felt to be critical to further progress in integrating pathways of care and improving the patient experience. Mechanisms and structures that support a coordinated approach to planning and delivering cancer care across local areas were called for. This is a role that cancer networks have generally fulfilled to date, but interviewees doubted whether they would do so effectively in the future given their decreased number and size and requirement to cover much larger geographical areas.

### 5. Planning blight

Interviewees stated that in the transition to the new system a decision-making vacuum has emerged which is causing planning blight, and a gap in the middle was opening up with the move towards a larger number of more localised commissioning bodies and smaller number of more distant regional bodies.

## 6. Transfer of public health to local authorities

The transfer of public health to local authorities was expected to create risks as well as opportunities. The potential loss of focus on the clinical elements of public health

### VIEWS ON THE REFORM PROGRAMME

While the main focus of the interviews was whether and how the reforms have affected cancer services in England, interviewees were keen to share their views of the reform programme as a whole. Given the scope and complexity of the reforms, it is unsurprising that they were not typically viewed as a single entity, but rather as a variety of different components which had been more or less positively received. Interviewees were generally more positive about the principle of greater clinical involvement in service commissioning and the stronger focus on clinical outcomes than they were about the new system architecture, the transition of public health into local authorities and the specific proposals for clinical commissioning groups (CCGs).

There was universal agreement that the current changes to the health service were of a different order and magnitude to any previous phases of NHS reform that could be recalled. A number of reasons were put forward for this. The first concerned the sheer scale of the reforms, with changes being implemented at the local, regional and national level and across commissioning, provision and public health. In the words of one interviewee, this has created a situation where there were 'no islands of serenity'.

Several interviewees noted how the challenge of implementing such far-reaching changes had been compounded by the absence of a clear policy narrative and an ongoing lack of clarity about major aspects of the reform programme:

*I've been in the NHS for a long time ... This is completely different [to previous reforms] and the main problem for people like me on the ground is we don't see what it's for. We don't see it has any purpose... I don't see any clinical or organisational purpose behind this, except a political one.*

(NATIONAL INTERVIEWEE)

*My frustration is that the government announced these changes now more than two years ago. We're eight, seven months away from pushing the button on the changes and we're all supposed to be working*

*in a shadow kind of way by October and there's still really a lack of clarity as to what all of this means ... These different newly formed bodies, what are they going to be responsible for and who's going to be accountable to who?*

(DIRECTOR OF PUBLIC HEALTH)

*No one's got any clear idea of senates... We're not quite sure what senates will do and clearly the national commissioning group are struggling to work out if we're going to have senates, what are they going to do? Where are they going to sit? And if you look at some of the papers that have come out it does feel a little bit like it's done on the back of an envelope.*

(NETWORK MEDICAL DIRECTOR)

### FUTURE COMMISSIONING ARRANGEMENTS FOR CANCER SERVICES

Particular concerns were raised about future commissioning arrangements for cancer, with continuing uncertainty around which aspects of the cancer pathway would be commissioned locally by CCGs, which would come under the remit of the specialised commissioning teams within the newly created NHSCB, and how the relationship between these two commissioning structures would work in practice:

*We don't really know who's commissioning what next year yet.*

(PHARMACIST)

*The current changes in specialised commissioning to me are a mystery. I know how it worked beforehand and I knew commissioners quite well, but how it's going to work in the future ... At the meetings I've been to they don't seem very clear about how it's going to work in the future.*

(PAEDIATRIC ONCOLOGIST)

*Even at this stage in the process of the reforms it's still not clear where responsibility for planning and commissioning of care is going to lie. So what's the extent to which clinical commissioning groups will commission cancer services?*

(NATIONAL INTERVIEWEE)

### REFORMS AT A TIME OF FINANCIAL AUSTERITY

In addition to these issues of scale and lack of clarity, a further distinguishing feature of the current reforms was their introduction at a time of financial austerity. Interviewees noted that, while the NHS had periodically

implemented Government reforms or made financial savings, it had never before been asked to achieve these at the same time. Meeting the target of finding £20 billion in productivity improvements would require large-scale service redesign, not just the identification of 'quick wins'. But there was a widespread sense that the capacity and skills to undertake this kind of work was being jeopardised by the disruption which the reforms had created locally:

*The reforms are putting a huge burden, an excessive cost and manpower burden, on an already financially stressed NHS.*

(NATIONAL INTERVIEWEE)

*So the reforms have clearly had a short-term, negative effect insofar as disruption to staff, relationships, responsibilities, structures, has made it more difficult for people to get together and make coherent, sensible, evidence-based solutions about restructuring services.*

(NATIONAL INTERVIEWEE)

It was against this context that the need for structural reform, especially in relation to commissioning arrangements, was questioned. While the aim of having more clinically-led commissioning was broadly supported, a number of interviewees maintained that this could have been achieved by adapting existing structures rather than creating new statutory bodies.

*There would have been a very simple solution which would have been to keep PCTs, strip out their existing non-executive boards and put in much more clinically-focused boards comprising mainly GPs. That would have achieved the same ends without the chaos that occurred.*

(NATIONAL INTERVIEWEE)

### IMPACT OF THE REFORMS ON FUTURE PROGRESS OF CANCER SERVICES

Interviewees were keen to point out that, despite the wider context, cancer professionals would continue to deliver good patient care. However, it was also felt that the reforms had stalled further progress in cancer care because they had created a climate of uncertainty and diverted time and resources away from longer-term service development:

*People are lacking in confidence to start anything new because they're not sure whether or not they're going to have a job... And I just think there's quite a lot of fear*

*out there to actually do any service development. It's kind of well, the fear to start it but also because you're constantly facing change and so it's very difficult to know how the landscape's going to look tomorrow let alone in 3 months time.*

(NATIONAL INTERVIEWEE)

*My assumption has been that this will just put in ... at the very least, two or three years of delay ... All the organisational memory for large chunks of the system is taking a retirement package. All the new people coming on don't know what jobs they're doing ... Cancer won't be their priority.*

(NETWORK MEDICAL DIRECTOR)

Some interviewees told us that their most recent local data had shown either a levelling off or slight decline of performance against some waiting times standards, particularly the 62 day referral to treatment pathway. At this stage it is unclear whether these data are a temporary fluctuation or are indicative of a longer-term trend, or equally how widespread any such trend might be beyond those areas. A clearer picture will emerge in the coming months, as waiting times data are aggregated and reported nationally.

### INCREASING FRAGMENTATION

Achieving coordination and communication across the patient pathway was felt to be essential to the delivery of high-quality cancer care and a positive patient experience. It was acknowledged that this called for primary, community, secondary and tertiary care providers within an area to work together as a whole system in the best interests of patients and their families.

There was universal agreement that significant progress had been made in recent years towards the planning and commissioning of cancer services along whole pathways of care, rather than on the basis of services delivered by individual organisations:

*The good thing is the NHS is now beginning to think about commissioning whole pathways of care, rather than individual contracts with individual organisations without any connections between them. So because there's now a focus on integrated care pathways that helps particularly the cancer agenda where people move between the system quite regularly and can do over time.*

(NATIONAL INTERVIEWEE)

## IMPACT OF THE REFORMS ON CANCER NETWORKS

Of the various factors that were mentioned as having driven and supported this shift towards a more pathway-based approach, the most commonly mentioned was the leadership and coordination provided by local cancer networks.

Views about cancer networks and their value varied (see the next section for a more detailed discussion). Nonetheless, many interviewees noted that the networks had achieved considerable success in bringing commissioners and providers together to plan services, which had helped to break down the organisational and professional boundaries that can inhibit joint working. In this respect, as one interviewee described it, networks acted as the 'glue that makes the system work'. Another commented that:

*Almost every pathway for any cancer you name has local elements and specialist elements. That in itself is complex. We need the CCGs working effectively together, and that's one of the things that networks are all about is bringing together the right people. So we need to make sure that we do maintain and strengthen what we've got in terms of networks.*

(NATIONAL INTERVIEWEE)

Despite the progress that had been made towards a coordinated approach in cancer, the most dominant theme which emerged from the interviews was a concern that the health reforms were starting to cause a fragmentation of cancer care – at both a local and a national level:

*Everything's becoming so fragmented, there are so many little pockets of everything.*

(NATIONAL INTERVIEWEE)

*But now... it's all fragmented. We've never been as fragmented as this before.*

(PCT CLUSTER COMMISSIONER)

*There's just that worry that, if we're not careful and we're not aware of it and we don't make the effort, there could be this fragmentation. And that's my watch word at the moment, it's the potential fragmentation and what we can do about it.*

(DIRECTOR OF PUBLIC HEALTH)

## COMPLEXITY AND RANGE OF NEW ORGANISATIONS COMMISSIONING CANCER SERVICES

It was widely commented on that several of the changes brought forth by the health reforms will have the effect of substantially increasing the number of organisations that are involved in planning, commissioning and delivering cancer services. Particular concerns were expressed that, in place of 152 PCTs, there will be public health teams based in local authorities, approximately 220 local commissioning bodies (CCGs) and an as yet unspecified number of commissioning support organisations.

Some commented that PCTs had 'reached a maturity' in how they worked together, understanding the importance of having a consistent approach to commissioning cancer services within a region. Lead commissioner arrangements were commended because they had enabled networks and providers to negotiate with a single PCT, acting on behalf of several other PCTs locally. While it was recognised that CCGs were still in a relatively early stage of development, doubts were raised about whether CCGs would foster a similarly collaborative approach. Several interviewees from provider organisations and cancer networks felt:

*What we don't want to do is to be negotiating with seven or eight different commissioning groups to continue our service and improve our service.*

(ACUTE TRUST LEAD CLINICIAN FOR LUNG CANCER)

Others suggested that the strong links that GPs have with their local communities could have detrimental, as well as beneficial, effects. Examples were shared where GPs were reluctant to support redesign or reconfiguration proposals which might result in a loss of services at the hospital local to their practice. This led some to question whether GPs and CCGs would be willing to make difficult strategic decisions about cancer service planning and investment.

It was not just the risk of fragmentation in commissioning structures and arrangements that raised concerns. Although some anxieties about private sector involvement were shared, the general view was that private sector provision would continue to develop relatively slowly in cancer care and be largely limited to specific services such as diagnostics and radiotherapy. What interviewees felt was far more likely was that CCGs would move certain parts of the patient pathway, such as diagnostics and follow-ups, from secondary into primary care. For example:

*I know that [CCGs are] looking at follow-up and I've heard GPs say that they don't see why cancer follow-up in many cases couldn't be in primary care. And whilst I'm sure there are a group of cancer patients who could and should be followed up in primary care, which ones should and shouldn't be should really be decided in collaboration with the specialist team. It shouldn't be an arbitrary thing, saying we will not pay for follow-up if x, y, z ... So I have concerns about follow-up.*

(NATIONAL INTERVIEWEE)

At issue was not the greater involvement of primary care in the delivery of cancer care per se. Rather, interviewees argued that the drive should be to deliver care in the most appropriate settings, according to clinical need and complexity, not simply to shift services into the community. It was also noted that, if attention wasn't given to how teams across different care settings would work in an integrated way, this could increase duplication and introduce delays into the pathway.

### THE ROLE OF NATIONAL LEADERSHIP IN DELIVERING CANCER SERVICES

Similar unease about fragmentation was expressed about the reorganisation of the cancer policy and support team at a national level. It is noteworthy that many interviewees felt that the development of a nationally coordinated approach to cancer, under the high profile leadership of Sir Mike Richards, had played a pivotal role in driving improvements in cancer services over recent years.

At the time of the interviews, the cancer 'headquarters function' was in the process of being split between the Department of Health, Public Health England and the NHSCB, while the National Cancer Action Team was preparing to move into the new NHS improvement body. The risks presented by these changes were summarised by one interviewee as follows:

*But I can tell you that one of the other threats is the size of team inside the Commissioning Board that's going to be working on cancer – it's going to be very small... The cancer board as a team in many ways will be split up – and I suppose this is another risk that we ought to be identifying, which is that the cancer programme has been fairly unified up until now ... And various different bits of the cancer world are going to be going in different directions at a national level ... It's a downsizing and a splitting.*

(NATIONAL INTERVIEWEE)

Another proposed that:

*There's not going to be a DH cancer policy team, as such. So the whole leadership and support and championing that we've had with the [National Cancer Director] in Mike Richards and the links he's had directly to the Department of Health and these other organisations like NCAT, NHS improvement and NCIN are all under threat.*

(NATIONAL INTERVIEWEE)

They went on to add that 'It's going to be two years from now before we have any real idea of what the impact of that is going to be.'

### THE 'GAP IN THE MIDDLE'

There was a widespread view that cancer services require effective coordination at a local level, to maximise the use of available resources, support a pathway-based approach, minimise treatment delays and ensure a positive patient experience. One interviewee explained why, as he termed it, a 'coordinating function' is so important in cancer, especially for more complex care:

*We have five oncology centres in the [area]. Each of them might want to develop a particular service, but in practice there may not be enough numbers. So, for example, prostate brachytherapy: you can't reasonably have every oncology centre offering prostate brachytherapy simply because there aren't the numbers for it and there isn't the expertise. There are some specialist treatments which you should and could quite easily centralise in, you know, one or two of those five places.*

(CLINICAL ONCOLOGIST AND TRUST LEAD  
CANCER CLINICIAN)

Interviewees broadly agreed that an infrastructure to support local coordination – both of commissioning activities and service provision – was essential, even though they did not always share the same view about what this infrastructure should comprise in practice.

A strong theme in many of the interviews was that a 'gap in the middle' is opening up with the move towards a larger number of more localised commissioning bodies and a smaller number of more distant regional bodies. Of particular concern was the loss of the functions carried out by cancer networks. At the time of the interviews, all of the networks we spoke to had seen a reduction in staff numbers, largely as a result of the management cuts and

post freezes. It was widely expected that proposals for the future of clinical networks – which were published towards the end of the fieldwork – would recommend a smaller number of networks covering several conditions including cancer, stroke and heart disease.

One interviewee felt that, while networks had played an important role in the development of a nationally coordinated approach to cancer, they had outlived their purpose:

*Do I think the networks should continue as they are now? No I don't. I don't think they fit with foundation trusts. I don't think they fit with clinical commissioning group structures. They're an old NHS system. They were great when they were introduced in the mid 90s for trying to standardise protocols for cancer and trying to standardise centre unit operation and pathways for cancer. So I think they did a really good job for about 10 years but I think their time is over... I have to say that in the contact I've had with [the network] they haven't added a lot of value quite honestly.*

(NATIONAL INTERVIEWEE)

A more common view – one expressed by both providers and commissioners – was that networks had generally been a valuable resource locally. Interviewees commented on a range of functions that they felt networks had usefully fulfilled including monitoring service quality and performance, providing support and expertise for service improvement and reconfiguration work, supporting implementation of national guidance, and acting as an 'independent arbiter' of cancer services. For example, we were told:

*I find the cancer network a tremendous resource ... It would be a tragedy if that was to be dismantled or diluted as a result of these reforms because they know cancer. They've been such an asset to us helping us to be expert commissioners.*

(PCT CLUSTER MANAGING DIRECTOR)

Local knowledge and engagement were regarded by many to be critical to the success of networks and that was felt to be at risk if networks were reconfigured to cover much larger geographical areas:

*I think the concern is that if networks aren't based around a clinical footprint it's very hard to get clinical engagement... They've got to map against*

*patient flows, otherwise they just become irrelevant.*

(PCT CANCER COMMISSIONER)

*Practically and knowing whether each region is delivering what the patients want, [networks] will be further away from that and unless they've got very sophisticated feedback mechanisms, and have armies of people out there asking penetrating questions, the services will start to lapse back into previously disorganised ways.*

(PAEDIATRIC ONCOLOGIST)

*Networks need to be big enough to have a coordinating function for the less common things, but local enough that you can reasonably say where they should be done ... There are all sorts of local issues that really need to be looked at nearer the ground. So for networks they ought not to be too big, because they become meaningless.*

(CLINICAL ONCOLOGIST AND TRUST LEAD  
CANCER CLINICIAN)

One interviewee argued that the likely future model for networks could lead to them losing a great deal of their local influence. She felt that their role would be largely limited to 'telling the system what is wrong, rather than working with them to get it right'.

Some suggested that networks had already started to lose some of their influence because of the reduction in staff numbers and prolonged uncertainty about their future. One interviewee told us:

*I am the only officer of the network who's been in post for any length of time because we've had locum medical directors. We now have a network director who is a medical director, but we have no lead nurse at the moment. We have nobody doing informatics and we have four posts which we cannot get filled, again, due to the obstruction or otherwise of the PCT.*

(COLORECTAL SURGEON)

## LOCAL LEADERSHIP AND CO-ORDINATION

Changes to networks, along with the clustering of PCTs and winding down of Strategic Health Authorities, were seen by several interviewees to have contributed to the weakening of local system leadership and coordination. One questioned where the impetus and leadership for large-scale service reconfigurations would come from:

*We need less acute trusts and you would close one or two and you would merge several ... The politicians have a hissy fit as soon as that gets on the agenda. And again, where is the ability to do those really big things that would improve care, would save millions and millions in this region? So under these new reforms, who's going to do that when each CCG is fighting their little patch, where's that overarching structure that can look strategically?*

(CLUSTER MANAGING DIRECTOR)

Others felt that this weakening of system leadership and coordination, in combination with the disruption caused by the transition to the new commissioning structures, had given providers greater freedoms:

*Providers are off their leash and there is no-one to hold the ring.*

(NETWORK MEDICAL DIRECTOR)

*There is no plan and people are working in a vacuum and they are making their own plans up.*

(NETWORK DIRECTOR)

A small number of examples were shared with us where providers had appeared to break away from joint working to pursue their own business interests. For example, one acute trust had recently purchased a new piece of high technology equipment, contra to a collective agreement by organisations in the network – reached after what was described as ‘a painful decision-making process’ – about the level of need for and location of this service.

However, not all provider-driven approaches had raised concerns. A number of interviewees commented positively on the recent creation in London of two provider-led collaborations, bringing together providers across primary, secondary and tertiary care to create integrated cancer pathways.

*The integrated cancer network [has] got a memorandum agreement between all the provider trusts that they'll come together... which may help as we aspire to commission whole pathways or bundles of pathways.*

(NETWORK DIRECTOR)

### **‘DECISION-MAKING VACUUM’**

Many interviewees also told us about the ‘decision-making vacuum’ that had opened up in their area,

due to a lack of clarity about where authority and responsibility for decision-making lay. Some noted that it was increasingly difficult to engage PCT commissioners as they were much reduced in number, often covering multiple commissioning briefs and having to split their time between the ‘day job’ and supporting the CCG development. Few of the PCT clusters interviewed had a lead commissioner for cancer services any longer.

*We've seen a drifting away of commissioners.*

(NETWORK DIRECTOR)

At the same time, interviewees stated that CCGs were overwhelmingly focused on the authorisation process and establishing their governance arrangements.

Therefore, amidst the transition to the new arrangements, it appeared that PCTs no longer felt they had the mandate to make major and/or long-term commissioning decisions but CCGs were not in a position to take over these responsibilities until they had achieved authorisation. In several examples shared with us, this uncertainty had resulted in planning blight. For example, one network had received a £180,000 grant from a national charity for a two-year service improvement project. However, the network could not get sign-off from the PCT cluster (who would have been the employing organisation) to recruit project staff to plan and carry out the work, and therefore the money had to be returned to the charity concerned.

Several more examples pointed to reluctance on the part of PCT clusters to authorise spending decisions.

*We identified six months ago where investment of £70,000 would save probably £170,000. It was all agreed at a meeting and by the time we had the next meeting, three months later, the whole thing had been put on the backburner because the PCT decided that it couldn't make a decision because of the transition to CCGs.*

(COLORECTAL SURGEON)

Some expressed particular concerns about the future of long-term capital investment projects, pilot services reaching the end of their initial funding and services that had been pump-primed by charitable organisations (with an agreement that longer-term funding would be taken over by PCTs). One charity told us about a successful local service they had piloted offering benefits advice to cancer patients, but that they were unable to ‘find anyone

to engage with' about long-term funding as the pilot was reaching its end.

### CCGS AND CANCER COMMISSIONING

A variety of issues were raised by interviewees when commenting on the transfer of local commissioning from PCTs to CCGs. Greater clinical involvement in service commissioning was broadly welcomed and potential benefits were felt to include better engagement across primary and secondary care and a strengthened focus on aspects of the cancer pathway that are most relevant to primary care (such as prevention and early detection). One patient representative interviewed felt that GPs were well suited to be commissioners because they, of all healthcare professionals, best understood the needs of their patients:

*We actually see it as positive because... the consultant process is a bit of a sausage machine, people get fed in and they get spat out. And the consultant doesn't know you. I mean, you might only see your actual consultant once maybe twice and then after that, it's a different registrar every time ... But your GP knows you, your GP knows what you need, the GPs understand what patients need.*

(CANCER PATIENT ADVISORY BOARD MEMBER)

A strong view emerged from the interviews that commissioning services for a complete patient journey is a highly complex activity, for which robust data and specialist expertise are essential. Although weaknesses in PCT cancer commissioning were acknowledged, it was also agreed that skills and relationships had substantially improved over the time:

*We saw with the change in commissioning which occurred eight years ago, and we moved to the commissioners that we currently have, there was a massive and prolonged learning curve... From last time, there were huge difficulties in getting involved with the new commissioners, for them to pick up expertise and learn to work with us, and we've really done that quite well over the past few years and for that to be all dismantled and go back to stage one again is depressing and worrying.*

(MEDICAL ONCOLOGIST)

Many interviewees were doubtful that GPs had a sufficiently detailed understanding and knowledge of cancer to commission services effectively at a local population level. A number suggested that GPs did not

fully understand pathways of cancer care because they predominantly saw cancer as a 'secondary care issue' or a 'referral issue'. For example, one person commented that:

*For a lot of GPs cancer has been something which they send you off to the hospital for.*

(NATIONAL INTERVIEWEE)

Others argued that GPs' commissioning expertise would be far stronger for conditions more commonly seen and/or managed in primary care:

*If primary care hasn't been very closely involved with cancer, they've got a very steep learning curve. They may find it easier to commission diabetes or asthma services, because they are very familiar with diabetes and asthma. Because the centre of gravity for cancer management has tended to be in secondary and tertiary care, GPs may just simply not know as much about the conditions.*

(NATIONAL INTERVIEWEE)

*[Cancer] is not their bread and butter. CCGs are made up of GPs so their bread and butter is mental health, cardiology and diabetes.*

(PHARMACIST)

Expertise in relation to rarer cancers was highlighted by some as a particular weakness, given that these patients often have the most complex treatment needs and pathways, and because GPs might see very few – if any – cases over their entire career:

*I have the highest respect for GPs but they don't, many of them do not have a detailed knowledge and understanding of cancer. It's not their ball game, they don't see enough of it or certainly of the rarer types. And you know they're not very close to cancer research either. Some will be but more won't be.*

(NATIONAL INTERVIEWEE)

Several expressed concerns about where the necessary knowledge and expertise was going to be found, especially at a time when many experienced colleagues had left the NHS, cancer networks were being substantially reduced in size and number and public health was moving into local authorities:

*There's no clarity about who's doing what. Is it a public health role? Is it a commissioning board role? Is it a*

*CSS [commissioning support service] role? What's in CSS's core offer? Have they been signed up to it yet?... It's all just a bloody big mess to be honest.*

(PCT COMMISSIONER)

It was noted that remaining sources of expertise – both clinical and managerial – would have to be shared by a much larger number of commissioning bodies. One interviewee feared that this would increase the risk of a postcode lottery:

*We've now gone up to, I don't know the current number of CCGs, 224, or something was the last number I heard. You're not going to get 224 GPs who really understand cancer and I think it's going to be really, it's going to be a lottery.*

(NATIONAL INTERVIEWEE)

Another suggested that experience and knowledge would be better in areas where GPs had already been involved in negotiating contracts for cancer services through practice-based commissioning arrangements.

The possibility was raised that, while CCGs are developing their commissioning expertise and/or looking to source external support, providers would come to exert a much greater influence over cancer services:

*CCGs... lack a great deal of knowledge... they don't understand complex areas of cancer. So I see the whip hand at the moment returning to secondary and tertiary care... That may change, but I don't see [CCGs] having the depth of knowledge in the medium term that the PCTs had and they've got other... fish to fry.*

(NETWORK MEDICAL DIRECTOR)

*This is what I think will happen: we will say what we think an ideal cancer service is for a particular cancer site, send that to the commissioners, and it's actually going to be very difficult for them to disagree with that.*

(CHEST PHYSICIAN AND LEAD CANCER CLINICIAN FOR ACUTE TRUST)

Perhaps unsurprisingly, interviewees from provider organisations were most sanguine about this scenario, often seeing it as an opportunity to open up local commissioning processes to the wider clinical community, including those with specialist cancer

expertise. However, as summarised in the previous section, there is also a risk that individual providers may respond to this opportunity by breaking away from a whole system approach and pursuing their own business interests. Were this to happen, it could end up increasing unnecessary and duplicated activity across a network area.

At the time of the interviews few CCGs had finalised their commissioning plans, but there were troubling reports that GPs in some areas were already starting to explore redesigning local pathways and services, including those for cancer. Several interviewees raised concerns about how this work was being tackled. Rather than looking holistically and strategically at care pathways and population needs, interviewees mentioned that specific services were being targeted in isolation in an approach that was variously described as 'dibbling and dabbling', 'tinkering' and having 'pet projects'.

*We're trying to get away from pet projects as well, which we weren't allowed to do obviously as a PCT. You were accountable and you went through the whole commissioning cycle. I'm struggling to see that happening.*

(PCT CLUSTER COMMISSIONER)

The examples gathered suggest that much of this new work is focusing either on managing referrals into secondary care or patient follow-ups after the acute phase of treatment. The main concern that interviewees shared was about the lack of a 'whole systems' view, which meant that changes might be made without an understanding of how they might impact on other interconnected aspects of the pathway.

In one area, for example, GPs had introduced a triage service for all gynaecological patients, including urgent referrals for suspected cancer. The proportion of patients with suspected gynaecological cancers being seen in secondary care within two weeks of their GP referral had decreased because of the additional time required to triage patients. This was proving difficult to resolve because GPs were not attending the multi-disciplinary team (MDT) meetings where patient cases, and the problems created by the triage system, were being discussed.

Interviewees recognised that CCGs were taking over commissioning responsibilities in a difficult financial climate. One interviewee, himself a GP and CCG Chair,

talked about the need to consider cancer spending against other healthcare needs and priorities:

*I pointed out [to secondary care colleagues] that there is a finite amount of money, I pointed out the demographic pressures and that cancer is likely to increase and I pointed out that you guys are going to blow our budget if you don't think carefully about evidence-based regimes, about saying when enough's enough. And if you're going to use £10,000 injection drugs and you're going to maybe buy an extra week of life, is it worth it?... In reality I'm also thinking about people with heart failure, with diabetes and other terminal conditions who are really poorly. Do they not have a right to healthcare too?*

(CLINICAL COMMISSIONING GROUP CHAIR)

As this quote indicates, CCGs face the difficult challenge of responding to increasing needs and expectations at a time of financial constraint. But some worried that GPs tended to perceive cancer care, particularly hospital-based care, as expensive:

*Their [GPs] immediate assumption about new technology – whether it's a new drug or a new piece of radiotherapy kit or molecular diagnostics – is that it's a cost, not a benefit.*

(NATIONAL INTERVIEWEE)

*For cancer, the worry about that is that GPs are generally much more interested in hip replacements and the common things ... also mental health care. Cancer, I think, is probably seen as very expensive ... So the worry is that this new commissioning process might well remove a lot of the funding from cancer and divert it to community-based problems like mental health and Alzheimer's, things like that.*

(MEDICAL ONCOLOGIST)

These, and other, interviewees argued that commissioners must balance cost against clinical and patient care considerations, so that the new treatments and technologies are fully and fairly assessed. The need for commissioners to understand 'benefit' in terms of reducing the harmful effects of treatment, as well as improving its outcomes, was also noted.

### IMPACT OF THE EFFICIENCY SAVINGS

Given the dynamic policy and economic environment of recent years, isolating the independent effect of cost-saving measures presents a formidable challenge.

Interviewees shared several important observations and experiences about how the £20 billion efficiency target was affecting cancer services.

A number pointed out that not only had cancer received substantial levels of investment in recent years, but that it had so far been relatively protected from financial cutbacks when compared to other clinical areas:

*I think people feel cancer's had a good whack of investment in recent years.*

(NATIONAL INTERVIEWEE)

*Our perspective is that cancer may have suffered less [from cost pressures] than some other disease areas, but the evidence for that is anecdotal rather than specific.*

(NATIONAL INTERVIEWEE)

One interviewee speculated that money was being taken from other budgets to ensure that cancer treatments were still fully covered in their area:

*In terms of providing treatments the money seems to be being found to provide all the NICE recommended treatments, so that isn't an issue. Where that money is coming from may be an issue because I suspect that some of the resources are being diverted from other clinical areas .. So I think that cancer services are probably being supported by cuts in other clinical areas.*

(CHEST PHYSICIAN AND LEAD CANCER CLINICIAN FOR ACUTE TRUST)

Although cancer funding was felt to be a very politically sensitive issue, there was nonetheless a general feeling among interviewees that cancer services could be provided more efficiently. Indeed, some suggested that the current financial situation could be viewed positively inasmuch as it had provided a fresh impetus for patient pathways to be redesigned and models of care improved. One interviewee proposed that innovation in healthcare delivery was principally driven by economic constraints:

*We know that innovation doesn't particularly happen at a time when there is lots of resource. It is the lack of resource that forces people to think innovatively to look for smarter ways to provide services. And there are a number of general and specific examples of how that's being addressed within cancer.*

(NATIONAL INTERVIEWEE)

Another, however, made a distinction between innovation in the sense of providing services more efficiently and the innovation which results in new discoveries and technologies. She suggested that the current environment was encouraging innovation in the former sense, but at the same time was starting to hold back groundbreaking work on the detection and treatment of cancer.

Many felt that efficiency programmes had increased the pressure to implement short-term cost-cutting measures, rather than focus attention on more complex pathway and service redesign which had the potential to both release resources and improve quality of care. Concerns about decisions being driven purely or principally by the need to achieve financial savings were frequently expressed:

*We're in a much more contested environment where first of all there's a general feeling there's no money around. Secondly if there is [money] there has to be a very very strong financial case produced to demonstrate that it will result in a quick, relevant outcome, and most quick relevant outcomes involve money. No matter that it's quality and innovation and all the rest of it. In the end it has to save money.*

(NATIONAL INTERVIEWEE)

*I've become concerned because of completely arbitrary decisions about new to follow-up ratios imposed by the commissioners who've clearly got in a panic over expenditure. Now I'm quite keen that we reduce unnecessary follow-up. I'm not keen that we make arbitrary decisions just based on... affordability.*

(NETWORK MEDICAL DIRECTOR)

Several examples were provided of how the pattern of service provision was being affected by the current financial context. But there was little evidence that changes being made to services were the outcome of robust de-commissioning processes. Instead, interviewees stated that 'panic decisions' were being made, and in some cases things had just 'dropped out of the contracts'.

It appears that rehabilitation and support services – including counselling and psychological care, dietetics and benefits advice – may be a soft target for spending cuts.

*We are more and more cost-conscious and cutting back on services rather than expanding them. So,*

*there's things like social support, dietetic – all those sorts of things which you should have in a good cancer centre, we don't have any longer, we have cut those back. Also cutting back on ability to recruit to trials; because of the workload, our consultants and junior doctors just don't have time to – in clinic – to do the extra work that's necessary for trials.*

(MEDICAL ONCOLOGIST)

*So in cancer care where you may have previously been able to deliver a lot of the psychosocial stuff, that is becoming increasingly more and more difficult... And then the concern is, well who is going to pick it up?*

(NATIONAL INTERVIEWEE)

Both these interviewees, and several others, expressed concerns that the services which were being reduced or withdrawn in their areas were those known to be most important to helping patients (and their families) live with and beyond cancer.

A further observation was made that – even where cancer budgets were largely insulated from financial pressures – the delivery of cancer care could nonetheless be negatively affected by cuts in other areas:

*Well we're all under pressure to do things more efficiently and that's right and proper because we are spending the public's money. The problem in the adult sector is that many of the hospitals are under such financial pressure that the operative slots become the safety valve for the hospital when they get over full and the operative slots then involve cancer patients as well as other patients with serious illness who are waiting for surgery, they get cancelled and sometimes multiply cancelled. [Interviewer: And do you know that that's happening locally?] Oh yes.*

(PAEDIATRIC ONCOLOGIST)

An important implication of this finding for any future work of this kind is that monitoring changes in the overall cancer spend is necessary, but not sufficient, to understanding how the efficiency savings may be impacting on frontline patient care.

## THE CANCER WORKFORCE

As with the NHS workforce in general, many cancer professionals have experienced considerable turbulence in recent years. Interviewees stated that significant numbers of staff had moved within or left the NHS

as a result of cuts in spending on management and administrative posts, the structural reform programme, reconfiguration of cancer networks and other changes to services made to deliver the efficiency savings target.

These changes were ongoing when our interviews were carried out, and further movement of staff – both within and out of the NHS – was anticipated over the coming months:

*On the provider side I've got staff that I'm dealing with that are going into their third or possibly fourth TUPE exercise, because they've been in a community trust that's joined an acute trust, that acute trust is now joining another acute trust and that acute trust is now amalgamating with another acute trust ... There is instability at all levels. And therefore the motivation and morale is affected at all levels and you've got lots of people potentially making decisions now that will affect years into the future who have no idea whether they're in a job next month.*

(ALLIED HEALTH PROFESSIONALS LEAD)

Many interviewees commented that, despite a great deal of resilience within cancer teams, morale and motivation had plummeted as staff tried to continue with 'the day job' in a climate of ongoing change, pressure and uncertainty.

*I think probably morale is the biggest thing and the loss of people who have taken voluntary redundancy and gone, so we lose that organisational memory.*

(PCT COMMISSIONER)

## MULTI-DISCIPLINARY TEAMS

The experiences shared with us suggest that two issues above all are affecting the cancer workforce: post freezes and pressure on certain specialist roles. Several interviewees told us that there had been a real-terms reduction in staff, partly because of redundancies, but more commonly because vacant posts were not being replaced. Comments of this kind were most frequently made about administrative and support posts, including MDT coordinators and data analysts:

*MDT support is under threat and has been axed or has been cut in a number of areas. And it's not necessarily that the job has been cut, it's someone has been asked to cover. So as opposed to having*

*an MDT co-ordinator covering two teams, for example, they might be being asked to cover four.*

(NATIONAL INTERVIEWEE)

*I've had a fight recently about [not replacing MDT coordinators]... We need to maintain our MDT personnel, they're a very skilled set of people ... Some patients are being deferred by a week because the MDT person hasn't been able to get all the stuff ready for that one or if there's a late addition you know they're unable to get that patient to MDT. So there may be an impact from that point of view that it starts to delay pathways by a week, maybe two weeks.*

(LEAD CANCER MANAGER FOR ACUTE TRUST)

Post freezes meant that existing staff were being asked to cover much larger workloads and evidence was shared about the impact this was having on services. Some interviewees – such as the one above – felt that the shortages in coordinator posts were introducing unnecessary delays into cancer pathways. Another commented that it was limiting face-to-face time with patients:

*Because of the lack of appropriate numbers of staff... our clinics are really getting almost unmanageable now... The time we can spend with each patient is much too short at the present time and we have great difficulty doing the extra things which are important, like planning, audits and clinical trials and all the other things which make a service good.*

(MEDICAL ONCOLOGIST)

## CLINICAL NURSE SPECIALISTS

The second issue that was raised – by many interviewees – was that cost savings appeared to be particularly affecting clinical nurse specialist (CNS) posts. CNSs were, in the words of one interviewee, under 'severe scrutiny' and many commented that such posts were being regularly reviewed and in some cases re-graded to a lower level. Concerns were voiced about pressures on CNSs not only to increase their responsibilities and workload within cancer teams, but also to cover gaps in general ward duties alongside their specialist cancer role:

*We've had this very marked and very specific targeting of any nurse who is a band 7 and above. It doesn't matter what you're called, what your title is, if there's a way to make you not that band, either subtly or unsubtly, then that will be found. So you've already, perhaps, lost some of your status, then your workload*

*is just steadily increasing and increasing with shifts of work that you might not previously have been responsible for... The dissatisfaction is not just personal, it's professional, because you never feel as though you're doing a proper job, you never feel that completeness that I have absolutely been able to do everything in my power to make this as good an experience as possible.*

(NATIONAL INTERVIEWEE)

*Specialist nurses have been an enormous advance in quality of care in a number of cancers, all cancers... In a number of areas they're seen as easy targets by the Trust to get them to go back and work on the wards, to do other work which is outside their specialist remit. I know of a number of posts which haven't been refilled. But I was thinking more of specialist nurses being asked to do things which aren't core cancer specialist nursing. So that's one example where the resource is being spread more thinly.*

(NATIONAL INTERVIEWEE)

*Macmillan posts have been restricted out of existence, again by this process of just generalising everything so that they're generic posts.*

(ALLIED HEALTH PROFESSIONALS LEAD)

A patient representative also felt that the wider multi-disciplinary team was very important to patients, and particularly vulnerable at a time of cost constraints:

*They [people with cancer] really need the help of speech and language therapists and physiotherapists and people like that and very often these people are in short supply before we start on the cuts.*

(PATIENT REPRESENTATIVE)

## WORKFORCE PLANNING

Interviewees stated that workforce planning in secondary care was increasingly being driven by cost considerations, with a targeting of staff into activities based on income and tariffs:

*Staff are being targeted more to beds and more to the acute care tariff than they are to being allowed to follow up outpatients and that's all part of the shaving of things to keep the cost base low.*

(NETWORK INFORMATION LEAD)

*So to some extent nursing posts and certainly admin and clerical and allied health professional posts are*

*extremely vulnerable, because they're seen as a cost saving that doesn't necessarily attract the income. Because the income comes with seeing patients in clinic or admissions.*

(PHARMACIST)

## IMPACT OF THE REFORMS ON STAFF

During interviews, when exploring whether the workforce issues described were having any impact on organisational performance, a number of interviewees noted that performance against national waiting times standards had – at least until recently – held, but this had required considerable additional effort from staff to ensure that patient care was not negatively affected by staff losses and turnover and the wider changes resulting from the NHS reforms.

As one interviewee explained, cancer professionals and staff were having to 'run very fast' to maintain performance. Another commented that:

*We're not running into huge delays in delivering radiotherapy or chemotherapy, but that's just because people are working six times harder. But I'm not sure that it's necessarily that the governance is being maintained or that safety... there are certain incidents that are happening.*

(PHARMACIST)

Several interviewees believed that this situation could not be sustained over the longer term.

## PUBLIC HEALTH TRANSITION

From 2013 onwards, local government will be responsible for providing and commissioning most public health services. At a national level, leadership and oversight of public health is moving from the Department of Health to a new independent body, Public Health England.

Interviewees welcomed the increasing emphasis on cancer prevention and early diagnosis, and acknowledged the vital role that public health teams were playing in this agenda. Against this context, views differed about what impact the transfer of public health teams to local government would have. For example, one interviewee felt that public health would be the beneficiary of greater attention and support from local councillors:

*On a plus side, I think bringing back the public health and local authority pre-1974 model is good ... If it's done well you can really have some synergy there*

*because local authorities, and in my experience the councillors there, are very passionate about the health and wellbeing of their communities.*

(PCT CLUSTER MANAGING DIRECTOR)

But another was concerned that the imperative of the electoral cycle puts pressure on local governments to demonstrate short-term outcomes. This, he suggested, might discourage investment in strategies where health improvements would only be realised in the medium to long term:

*You know if you get more kids doing PE at school you're not going to see their health outcomes for a long time and whether that will be high enough on local authorities' radar when they've got an election to win in four years' time I don't know.*

(PCT CANCER COMMISSIONER)

Many anticipated that local authorities would take a broader view of public health than PCTs had done, integrating health promotion with areas such as housing, employment, transport and regeneration. For some, this approach had significant potential by focusing attention onto the wider determinants of health and wellbeing.

## CANCER PREVENTION

More commonly, however, interviewees expressed concern about a possible loss of focus on the more medical aspects of public health practice, which were felt to be central to cancer prevention. In particular, they expressed doubts about the future of smoking cessation and healthy eating programmes and initiatives to encourage screening attendance:

*I think there's a distinct possibility... that in local government there will be a different set of priorities that will be still relevant to cancer but more upstream. When you think of the work in raising awareness that's been done through public health in the past few years, I do wonder whether that will happen after 2013.*

(NATIONAL INTERVIEWEE)

*My two areas of interest are CVD and cancer. I will lose all of the influence really that I have on that because of the move into local authorities where my main role is going to be about considering the wider determinants of health and, in my view, moving away from the more clinical aspects of public health which is around case finding, pathway development,*

*screening, which I won't have a direct responsibility for. I'll just be holding CCGs to account on... It strikes me as I learn about what might be my new role in my council, a lot of the clinical aspects of public health that I've been trained to do and is actually my first love, it won't be part of my gig, it just won't be part of my brief. So that does worry me an awful lot.*

(DIRECTOR OF PUBLIC HEALTH)

This might help to explain why some clinically trained public health specialists were re-training or taking posts elsewhere in the NHS rather than moving into local authorities. One interviewee worried that the local authority approach would make public health a less attraction option for medical trainees, which might further 'de-medicalise' the public health workforce:

*At the moment, we have both clinical and non-clinical... people coming into public health as consultants and that's very rich, it's the perfect world. But I think more and more we'll see young people who go through their medical training not choosing public health as a speciality because why would they?*

(DIRECTOR OF PUBLIC HEALTH)

These issues were also reflected in concerns about where accountabilities for preventive services would lie. For example, a number felt uncertain about which body would be accountable for screening programmes and patient uptake at both the national and local level. Clarification was needed not just about delivery of preventive programmes but also about who would collect and have access to data to monitor their effectiveness:

*From a public health perspective that shift [to local authorities] is going to create all sorts of havoc with data that allows us to monitor the impact of public health initiatives... For cancer we are very concerned that you won't know any longer with the same certainty the level of screening participation or uptake of vaccinations of HPV [Human papilloma virus] for example. And in a few years time we will not have the quality of understanding of our public health initiatives around cancer that we do at the moment.*

(NATIONAL INTERVIEWEE)

Finally, interviewees cautioned against public health in local authorities becoming 'isolated' from NHS commissioners and professionals. The importance of CCGs and primary healthcare teams having easy access

to public health expertise was emphasised which, some felt, would need careful consideration of how public health teams would work across organisational boundaries.

## CANCER AWARENESS AND EARLY DIAGNOSIS INITIATIVES

The principle of having a National Awareness and Early Diagnosis Initiative (NAEDI) was one which received universal support. Several interviewees argued that targeting improvements at the earliest stages of the pathway was vital to improving cancer outcomes. It was also, as one interviewee noted, addressing a key patient priority:

*In our consultation exercises with teenagers and young adults and children's families, delays in diagnosis is their overwhelming number one priority in cancer service development. They feel that people aren't listening to them and they're often disregarded. And then ultimately being told you've got cancer after being disregarded is a pretty wounding experience. So I think the early diagnosis initiative which has been given a lot of energy by the CRUK and the government together has been a very good development.*

(PAEDIATRIC ONCOLOGIST)

Many felt that the value of the NAEDI programme had been to give cancer prevention and early detection greater focus, momentum and a higher national profile.

Interviewees often drew on very current experiences because our interviews took place soon after the launch of the national bowel cancer awareness campaign (January 2012) and during the launch of the national lung cancer awareness campaign (May 2012). In all the case study areas, these public awareness campaigns had encouraged people to consult their GP and, consequently, had substantially increased the number of suspected cancer referrals.

The increased activity that had been generated in secondary care was described by one interviewee as a 'tsunami level of referrals'. Another commented that there had been a 100% increase in referrals for colonoscopies during the first two weeks of the bowel cancer campaign. While areas had received increased resources to meet the anticipated rise in demand, in all cases these were felt not to have been sufficient.

The outcome was to have put significant additional pressure on already stretched NHS staff and services:

*I mean the bowel screening campaign did create an increased number of patients attending with symptoms and it also created a huge increase of number of referrals to secondary care. Which caused a strain on the services and obviously it was a ... well inevitably more delays in the system. And it didn't actually create any increased number of cancers that were identified. So it just created a lot of demand in the system without actually producing the desired benefit.*

(GENERAL PRACTITIONER)

A small number expressed concerns about how this had affected patients waiting for tests on other clinical pathways. For example, one interviewee commented that the increase in the number of patients receiving urgent referrals for suspected cancer had resulted in other groups of patients needing to wait far longer than usual for diagnostic tests. Their area was still clearing the backlog of colonoscopy referrals months after the bowel cancer awareness campaign had commenced.

Another pointed out the inconsistency between the messages of the NAEDI campaign and national clinical guidelines for referral for suspected bowel cancer:

*The campaigns haven't been based on NICE guidance, of evidence-based guidance. For example the [bowel cancer] campaign urged people to visit their GP if they'd had diarrhoea for 3 weeks. Well, the referral criteria is it has to be at least 6 weeks before referral. It just seemed to me a really unhelpful time to be doing this.*

(GENERAL PRACTITIONER)

Where data could be shared about the outcomes of the NAEDI campaigns, it presented a mixed picture. Some reported that, while campaigns had increased referrals, they had not had any impact on detection or early diagnosis rates. One interviewee told us that there had been an increase in the detection and removal of colonic polyps, which is a potential precursor of colon cancer. Another area had tracked a 13% shift in diagnosis of colorectal cancer from stage 2 to stage 1, an outcome of statistical and clinical significance.

## THE CANCER DRUGS FUND

Interviewees stated a range of views about the introduction and impact of the £600 million Cancer Drugs Fund, introduced to pay for drug treatments not or not yet approved by the National Institute of Health and Clinical Excellence (NICE). A few interviewees stated that the fund had achieved its stated aim of improving patient access to cancer drugs and, in doing so, had taken the pressure off clinicians to say 'No' to patient requests for non-approved treatments.

Yet there were also several concerns. Some argued that the creation of the fund had sent out an unhelpful message to the public: namely that whatever the financial state of the NHS, they could expect to access cancer treatment come what may. It was noted by one interviewee that this directly contradicted how local NHS organisations were justifying and explaining the need for priority setting, which is that difficult decisions about services would have to be made to meet growing demand with limited resources.

Another felt that the fund was being used by doctors to put off having 'honest and difficult conversations' with seriously ill patients about initiating palliative and end-of-life care. He and a number of others raised concerns about the value of some of the drugs being paid for through the fund, given that their clinical effectiveness had not yet been assessed by NICE. In particular, it was suggested that the fund might be exposing patients to drugs with unknown – and potentially unacceptable – toxicities, which could do more harm than good.

Many of these issues were encapsulated by a network medical director who concluded that:

*The cancer drugs fund is... appalling commissioning... It has widened access to high-cost probably relatively ineffective drugs. To my mind it puts out all the wrong messages... On the one hand you're saying doctors put the brakes on, we've got no money. On the other hand they're saying but here, use these very expensive, ineffective drugs.*

(NETWORK MEDICAL DIRECTOR)

It was also noted that the process of having local areas decide which drugs the fund will pay for sat uneasily with the emphasis on having nationally agreed standards of care. One interviewee commented that, as a result of this approach, the fund had 'caused a lot of angst' for patients who were unsure about whether a particular drug was covered in their area or not.

## THE FUTURE FOR CANCER SERVICES

The final question posed in our interviews asked interviewees what they felt was needed to enable further improvements in cancer services and outcomes at a time of ongoing change and financial pressure. The answers given contained three dominant themes, and a number of more specific suggestions.

In terms of the overall themes, the first was that NHS organisations needed a period of stability to get on with implementing the reforms and start rebuilding relationships. This didn't have to mean no change per se, just no more top-down change:

*Stop changing everything all the time, because we don't seem to stay still for any length of time. Yes, we should be constantly improving, but that should be driven by people like me, not people like Andrew Lansley.*

(CLINICAL ONCOLOGIST AND TRUST LEAD  
CANCER CLINICIAN)

Secondly, a number of interviewees argued that the progress which had been made in cancer had been underpinned by a host of positive developments such as the National Cancer Plan, peer review, multi-disciplinary teams, clinical nurse specialists and waiting time standards. What was needed, therefore, was continued focus on embedding these improvements in the organisation and clinical delivery of services:

*I don't think we need great changes – we've got peer review, we've got site-specific groups, we've got multi-disciplinary working, we've got cancer leads. We've got all the things you really need that, to be honest, isn't present in any other country. It should be fabulous but we're really struggling under the pressure of increasing demand which is making the whole system creak.*

(MEDICAL ONCOLOGIST)

*For the average patient coming through the hospital has improved quite considerably over the last 5 to 10 years with the national cancer plan being put into action. So the presence of multi-disciplinary team meetings for all cancer cases, the timetable of events, the two-week wait, the cancer starting treatment times and all the rest of it have had a significant impact.*

(PAEDIATRIC ONCOLOGIST)

**CLARITY ABOUT ROLES, RESPONSIBILITIES, RELATIONSHIPS AND ACCOUNTABILITIES**

The last general theme was a call for greater clarity about roles, responsibilities, relationships and accountabilities in the new NHS infrastructure. In particular, it was felt that service planning and redesign was being hampered by ongoing uncertainty about the respective responsibilities of the NHS Commissioning Board, CCGs and other organisations involved in the commissioning of cancer services. On this issue, a small number of interviewees made the case for more aspects of cancer care to be commissioned at larger population levels by specialist commissioning teams:

*I would like to see more specialised commissioning over the board.*

(CHEST PHYSICIAN AND TRUST LEAD CANCER CLINICIAN)

# HAVE THE NHS REFORMS AND EFFICIENCY SAVINGS HAD AN IMPACT ON CANCER SERVICES?

The NHS is presently a health system in transition. It is intended that the health reforms introduced in 2010 will be fully implemented by April 2013, and the deadline for the service to find £20 billion of efficiency savings is currently set at 2014–15. More change is also likely in the future, with ongoing operational and financial challenges expected to drive service closure, major service reconfigurations and a wave of mergers and acquisitions in the provider sector (e.g. Ham 2012). Past experience also suggests that CCGs may come under pressure from above to merge into a smaller number of commissioning organisations, more closely aligned with local authority boundaries.

The full scale and effect of these changes will not be known for many years yet. Nonetheless, this report has provided an insight into the early impact that the health reforms and efficiency savings may be having on cancer services in England. The data gathered tells a mixed story.

The performance of cancer services against national waiting-time standards has – for many indicators – held or even slightly improved over the last two years, despite increasing numbers of patient referrals. The main exception to this is waiting times for endoscopic diagnostic tests, which started to increase in mid 2010 and have yet to return to previous levels.

But performance data do not reveal the full picture of the effect that the reforms and efficiency savings are having on cancer staff, services and patient care. As Doherty points out, ‘Measuring performance through quantitative criteria such as waiting times rather than input or qualitative criteria can undermine the value of work that is non-measurable and non-visible. This is because quality counts far less than quantity in respect to the targets upon which an organization’s success is judged’ (2009: 1135).

The findings from our interviews with national and local stakeholders raise questions about the cost at which service performance is being held, as well as the long-term sustainability of this situation. Several themes dominated our interviews, including concerns about local and national fragmentation, loss of cancer knowledge and expertise, the difficulty of developing and improving services in a climate of ongoing uncertainty and poor staff motivation and morale. While there was a widespread feeling that cancer may be more insulated from funding pressures than other areas, it appears that some services are soft targets for cuts, including administrative and clinical nurse specialist posts and rehabilitation and support services.

The general view that emerged from our interviews was that these and several other factors have stalled improvements in cancer services, with estimates of anywhere between 18 months to 3 years for recovery to occur. There is a pressing need for greater clarity about roles, responsibilities and accountabilities within the new system architecture. This is essential to overcoming the barriers to long-term and coordinated planning which cancer professionals and staff are currently contending with.

## INSIGHTS FROM EVIDENCE ON LARGE-SCALE ORGANISATIONAL CHANGE AND REFORM

It remains to be seen to what extent the issues uncovered by this research are the effects of the specific reforms outlined in the Health and Social Care Act, or the outcome of large-scale change per se. This question is important because changes resulting from the reform process might be expected to be temporary, whereas if they are caused by the reform content they may be more permanent. Published evidence on the impact of large-scale organisational change provides some useful insights here.

The evidence base on the impact of large-scale organisational change is not vast, and even more sparse in relation to healthcare. Nevertheless, a review of the literature identified a number of useful studies and reviews which revealed several common findings. These can be categorised into two overarching themes – impact on staff and impact on organisational performance and service delivery – which are examined in turn below.

### **Impact on staff**

Most of the literature reviewed under this theme focused on the emotional and psychological effects on staff of large-scale organisational change or public service reform. A range of emotional and psychological responses to organisational change have been reported (French 2001), but major change is most commonly characterised by negative staff emotions (Smollan et al. 2010). Even where emotions are positive, staff can still experience ‘change burnout’ (Halbesleben and Buckley 2004), especially where reform is ongoing or changes are concurrent.

Woodward and colleagues (1999) reported that large-scale change increased job demands and insecurity over time and, as a result, staff experienced increasing levels of psychological distress, which also impacted on family life. When the workplace environment was examined, they found that this deterioration in psychological wellbeing strongly correlated with decreased supervisory support and a significant decline in team work, role clarity and social support as organisations were reorganised. Idel and colleagues (2003) also pick up on the theme of job insecurity and the perceived threat that organisational transition and change can cause. Their study compared nurses transferring to a new employer, following organisational merger, with a control group of nurses who were not affected by the merger. The former, they found, showed significantly higher levels of emotional distress, which was linked to perceptions of job insecurity and feelings of burnout, stress, lack of energy and adjustment difficulties.

The timescales set to implement organisational change are also important. Kiefer (2005) found that when change occurred too quickly or was poorly timed, it could result in anxiety and anger. Equally, where change was protracted, staff often experienced prolonged anxiety or despair as continual adaptation to ever-changing work situations was required. Wolfram

Cox (1997) also reported on time-related impacts, suggesting that changes introduced too quickly and/or without sufficient communication, engagement or preparation had negative emotional and psychological effects on staff. A number of studies point to the burnout effects of frequent change, with reported reductions in staff commitment to further change, job satisfaction, psychological wellbeing and sickness absence levels (Herold et al. 2007; Rafferty and Griffin 2006; Verhaeghe et al. 2006).

Evidence on mergers – which have dominated NHS reforms for nearly 20 years (Fulop et al. 2002) – show an even more acute response to change and uncertainty. Cartwright and Cooper (1993) used the British Psychiatric Rating Scale to measure the psychological symptoms of staff going through mergers. They found that staff had substantially higher scores than the normal population in relation to anxiety and hysteria and that those in managerial posts were most adversely affected. The main issues reported by managers were too much work; not being able to ‘switch off’ when not in work; and uncertainty due to a lack of consultation and communication. Clinical professionals are not immune from acute psychological responses. Rathod and colleagues (2011) found heightened stress levels resulting from service changes in a group of psychiatrists, including an increase in suicidal thoughts.

Turning our focus to the impact of changes on employee behaviour, Franco and colleagues (2002) suggest that staff motivation is a critical component of health system performance but can be negatively affected by large-scale reforms. Their conceptual review points to the risks posed by health sector reform on worker motivation, including that resulting from uncertainty, poor communication, loss of leadership and dissonance between staff values and reform goals. Focusing on the impact of restructuring processes and stressors on job satisfaction among hospital-based nursing staff, Burke (2003) found that the key moderating factor was that of perceived organisational support. When staff felt they were being supported by their organisation they were more satisfied with their jobs and reported less stress. However, when the organisation was not perceived to be supportive, this produced more negative feelings about the workplace and led to deterioration in the relationship between staff and their employers.

### **Impact on organisational performance and service delivery**

Studies exploring impacts on organisational performance and delivery are fairly unequivocal about the disruption caused before, during and after large-scale change and suggest that, consequently, any positive effects of reorganisation may take some time to be achieved. Intermediate effects of change include disruption to management routines and practices, distraction from a focus on services, disruption to services, problems with service and systems integration, issues with working practices and negative impacts on equity and access to services (Andrews and Boyne 2012; Fulop et al. 2002; Garside 1999; Hannan and Freeman 1984; McClenahan 1999; Zajac and Kraatz 1993).

Examining the short- to medium-term impacts of local government reorganisation, Andrews and Boyne (2012) report poor morale, loss of managerial expertise, distraction from core service provision and work overload. They point out that these impacts were made worse as a result of serial restructuring, where the consequences of previous or concurrent structural changes had not yet been fully worked through or completed. Significantly, they found that disruptions begin to materialise early on in the change process and prior to the formal establishment of new organisational arrangements. Reports vary as to how long it takes for performance to return to pre-change or merger levels, with most suggesting between 18 months (Fulop et al. 2002; Braithwaite et al. 2005) and 3 years (Andrews and Boyne 2012; Cartwright and Cooper 1990, 1993).

Looking at drivers for merger, Ferguson and Goddard (1997) identify economic gains through economies of scale and reduced management costs, as well as the rationalisation of services by reducing excess capacity. But the likelihood of these gains being realised is not borne out by the evidence, with 50–80% of mergers considered to be financially unsuccessful (Cartwright and Cooper 1990). The Andrews and Boyne study described above found that reorganisation led to a sharp deterioration in service performance and was associated with higher expenditure and poorer value for money. This appeared to have an impact both in the period leading up to reorganisation as well as over time. Similarly, Fulop and colleagues (2002) found that – some two years after merger – an NHS trust had still not achieved a key objective of saving £500,000 a year in management costs. Also on this issue, Goddard and Ferguson (1997) found only small reductions in management costs after mergers in the NHS.

### **What can we learn from the evidence?**

The evidence presented suggests that there is no substantial difference between the impact of the current health reforms as reported by staff working in cancer services and those experienced by staff during previous reforms or other large-scale organisational changes. This then raises two different questions:

- If we already knew about impacts of large-scale change, could any of these problems have been prevented?
- How can we use this wider learning to better prepare for large-scale change and transition, and manage it more effectively?

The literature review findings suggest that, while not all negative impacts can be prevented, there are nevertheless actions that can make a difference. In particular, it points to a developmental and human response to change that takes account of both the organisational needs as well as those of the individual.

At the level of the organisation, evidence supports an approach which sets out a clear vision, strategy and culture for change, together with effective leadership and clear structures (Choi 2011; Waclawski 2002). Fulop and colleagues (2002) report that an organisational culture focused on process as much as outputs can be helpful in managing change, as is a positive attitude to risk taking and innovation. An emphasis on organisational learning and opportunities for staff participation and involvement can also facilitate change processes and help to alleviate some of the negative effects reported above.

At the level of staff, Whelan-Berry and colleagues (2003) call for a greater understanding of what motivates and drives individual change, while Terry and Callan (1997) argue for time and a proper process that enables staff to adjust to their new environment and ways of working. In addition, we know from good practice in organisational change and mergers that frequent communication, strong leadership presence and other organisational interventions that provide support and build trust through difficult transitions can play a positive role (Cartwright and Cooper 1993; Cortrivid 2004; Franco et al 2003).

## LOOKING FORWARDS

Significant improvements have been made in cancer services in England in recent years, but gaps still remain. Future improvements will have to be made in a more challenging financial environment and at a time of rising public demand and expectations. The extent to which further progress will be enabled or obstructed by the changes brought about by the health reforms will only become clear over time.

This report suggests that the health reforms may present both opportunities and risks to cancer services and professionals. A number of areas of concern were identified by those interviewed – nationally and locally – which need to be better understood in the present as well as monitored over time.

For example, the combination of far-reaching organisational change and reductions in management posts has led to a partial loss of expertise and local knowledge of cancer services, particularly in commissioning structures. As commissioning responsibilities transfer to CCGs, so the question must be addressed as to where the skills to effectively commission cancer care pathways will be found. This also opens up the issue of how cancer networks will function in the future, alongside considerations about the role of new bodies such as commissioning support organisations and clinical senates.

Our findings also show that the clinical nurse specialist workforce is coming under increasing scrutiny and pressure to take on more general ward duties in the search for financial savings. This is despite evidence of the critical role that CNSs play in coordinating and personalising patient care. Indeed, the most recent National Cancer Patient Experience Survey reported that:

*On almost all questions, patients with a CNS give more positive scores than do patients without a CNS. The scale of these differences, between those with a CNS and those without one, is very substantial and has been maintained over the two surveys. The findings are the clearest possible indication of the quality of care given by specialist cancer nurses, the manifest impact that they have on the services given to cancer patients, and the substantially improved understanding of treatment options and prognosis which flow to patients from contact with their CNS.*

(DEPARTMENT OF HEALTH 2012: 18)

Any reductions in MDT posts – clinical or administrative – must not negatively affect the quality and delivery of frontline patient care, and such assurances should be sought by CCGs when commissioning cancer services.

The scope for cancer care to be provided more efficiently was acknowledged by many of those interviewed, and it is a key driver of local pathway redesign. But at a time when the NHS is under substantial pressure to make financial savings, there is a risk that the emphasis is placed on making cuts rather than delivering greater value for money. A long-term view of efficiency savings must be taken. For example, the high costs of new technology may be offset by decreased spending on hospital stays and reduced complications (Rosen et al. 2006). Given this, new technology should be seen as an investment as well as an expenditure.

Early indications are that, for patients with long-term conditions, GPs may be looking to reduce hospital referrals and deliver more services in community settings. If such approaches are taken for cancer, and the experiences shared by some interviewees suggest that they may be, these must not be at the expense of efforts to achieve a more coordinated and streamlined approach to patient care. It will also be important to establish what developments in skills, capacity and facilities are required to support more cancer care in the community.

To this end, more fully integrating primary care teams into cancer MDTs is vitally important, as is input from secondary and tertiary care professionals in local strategic planning and commissioning decisions. Recent research provides evidence that poorer cancer outcomes in countries such as England and Denmark may be a consequence of primary care gatekeeping systems (Vedsted and Olesen, 2011). This has important implications for GPs and CCGs when reviewing cancer pathways as it suggests that the problem may be too little, rather than too much, referral.

Above all, there is a very real possibility of fragmentation in cancer services at both a local and national level. There is a need to ensure that the right structures, levers and incentives are in place to enable and encourage joint working. Equally, the issue of who will provide the local system leadership and coordination on which integrated models of cancer care depend must be addressed. These should be urgent priorities for NHS leaders and policymakers as implementation of the reforms progresses.

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# APPENDICES

## APPENDIX 1. METHODOLOGY

### Overview

Cancer Research UK commissioned an independent research team to assess the current and likely future impact of the health reforms and efficiency savings on cancer services. The key research question was: are cancer services in England improving or deteriorating during the NHS reforms and the drive to achieve efficiency savings?

The evaluation of complex health system interventions, such as policy reform programmes, is a far from simple task, and there is unlikely to be a single approach that can definitively and unequivocally determine impact (Walt et al. 2008). A particular challenge for this research was that NHS staff and services were being affected by a raft of different, but often interlinked, changes taking place within both the NHS itself and the broader economic and political environment. Moreover, the NHS reform programme itself includes many different elements that might be expected to have variable impact on cancer services in England.

It is difficult – if not impossible – to fully disentangle, isolate and independently assess the effects of the many changes that may be affecting the commissioning and delivery of cancer services in England at present. Nonetheless, the early impact of the health reforms and efficiency savings was assessed through a mixed methods study comprising two main elements:

1. Analysis of routinely available datasets on cancer services performance and cancer expenditure from April 2010 to present
2. Exploration of the experiences and perceptions of local and national stakeholders regarding the introduction and ongoing implementation of the health reforms and efficiency savings.

Additionally, a review of published literature on large-scale organisational and system change was carried out, yielding evidence with which to contextualise the research findings and consider the likely future impact of the changes currently being implemented in the NHS.

### Analysis of quantitative datasets

Published data for the periods 2010/11 and 2011/12 were examined relating to: i) cancer waiting times and ii) diagnostic test waiting times. The datasets used in this report are published by the Department of Health and are used to monitor progress against national Cancer Waiting Time Standards which were introduced in 2000, and reaffirmed in 2011. The data covers a number of aspects within the secondary care environment; there is very little data on the primary care pathway. The methodology followed was a graphical and arithmetic review to discern longitudinal patterns and trends, with a particular focus on the period following the announcement of the NHS reforms (July 2010 onwards).

Additionally, publically available NHS programme budgets for the years 2007/08 to 2010/11 were analysed. This review consisted of:

- The measurement of the year-on-year growth/decline in the overall budget in both nominal and real terms. This provides background information on the amount of resources that are being spent on healthcare.
- A year-on-year review of the proportion of the overall budget allocated to cancer services. There is considerable competition for resources within the healthcare environment. This proportional analysis

describes how cancer services compete with other demands on the budget.

- The measurement of the year-on-year growth/decline in the total monetary amount allocated to cancer services in both nominal and real terms and the resulting expenditure per capita. Real-term spend per capita provides a view of cancer spend that excludes the distorting effects of inflation and population growth.
- An analysis of the expenditure on cancer services by individual PCTs across the period. Spend by PCT highlights any regional or geographic difference in cancer spend and allows follow-up queries to individual PCTs.
- A description of the total expenditure on cancer services by care setting. This element of the review used data first published for the year 2010/11. It is presented as a guide only given definition problems with new data.

### Qualitative interviews

Views and experiences of the health reforms and efficiency savings were explored through interviews with cancer experts at a national level and in the eight case study cancer network areas. The selection of networks was based on the principle of maximum variation sampling, a purposive approach which seeks to select 'cases' to include the widest possible range of characteristics, thereby maximising diversity in the sample. Sampling is guided by an understanding of the likely factors that might affect experiences and perspectives, and seeks to include as many of these as possible. For this research, these factors included the following network area characteristics:

- Socio-economic characteristics: e.g. networks with more and less affluent populations
- Demographic characteristics: e.g. inclusion of networks with a high proportion of older residents and with relatively large black and minority ethnic populations
- Environmental characteristics: e.g. networks with differing urban : rural population ratios
- Service-related characteristics: e.g. inclusion of networks with recognised good practice in cancer services, and high and low survival outliers.

A total of 52 people took part in either a face-to-face or telephone interview between April and August 2012. Interviewees were selected to ensure a variety of different roles and perspectives and the final sample included the following:

- Cancer network directors
- Other members of network teams including medical directors, nurse leads and service improvement leads
- Patient representatives
- Surgeons, oncologists and specialist physicians
- Clinical nurse specialists and lead cancer nurses
- Specialist allied health professionals
- Public health directors
- Pharmacists
- PCT and specialist commissioners
- GPs in clinical commissioning groups
- Professional organisations and royal colleges
- National policymakers
- Patient charities

The interview topic guide comprised an introductory and four general questions, supplemented with additional questions to clarify responses and explore issues in greater depth (see Appendix 2). Interviews lasted on average 45 minutes and, with participants' permission, were digitally recorded; they were then transcribed verbatim.

Thematic analysis of the interview data was carried out, guided by the principles of Ritchie and Spencer's (1994) Framework Approach. This involves the initial identification of analytical themes derived from the research questions and existing literature, to which additional themes are added as new insights emerge from the data. The value of this approach is that it is particularly well suited to the problem-oriented nature of applied and policy-relevant research, whilst also allowing for an analytical process which remains grounded in and driven by participants' accounts.

## APPENDIX 2: INTERVIEW TOPIC GUIDE

### Question 1.

**Aim:** Capture background information about the interviewee.

**Main question:** Can you start by telling me a bit about your current role and main responsibilities?

**Possible probes:**

- Clarify which 'role' we are interviewing them in
- How long have they been in current position?
- How much contact/involvement with cancer services at a local level?

### Question 2.

**Aim:** Explore current state of and issues affecting cancer services.

**Main question:** What do you see as the main issues and challenges facing cancer services in England at present?

**Possible probes:**

- Views about current proposals for cancer networks
- Do they think the aims of the cancer outcomes strategy are achievable?
- Progress on prevention, awareness and early diagnosis

### Question 3.

**Aim:** Explore perceived impact of the health reforms and efficiency savings on cancer services in England.

**Main question:** The key issue that this study is exploring is the early impact of the NHS structural reforms and efficiency savings on cancer services in England.

- What in your view are the main goals of the NHS reform programme?
- From your experience in the role of [...] have the current reforms, and/or the efficiency savings, had any impact on cancer services? In what ways?

**Possible probes:**

- Fit between NHS reforms and cancer-specific reforms (reinforcing or conflicting?)
- What opportunities and threats do the current reforms pose for cancer services?
- Could the reforms have any unintended consequences (positive or negative)?
- Is their organisation gathering any data/evidence that has shown an impact?

### Question 4.

**Aim:** Explore the perceived differences between the current changes and previous phases of NHS reform.

**Main question:** Would you say that there is any difference between the impact of the current changes in the NHS and previous NHS reforms?

**Possible probes:**

- Are there any previous changes in government and NHS policy that compare?
- Comparison with previous NHS reforms – what is similar and what is different?
- What is the 'added impact' of the efficiency savings?

### Question 5.

**Aim:** Gather suggestions about the factors that will sustain improvements in cancer services.

**Main question:** How can improvements in cancer services be sustained and built upon as the NHS reform programme is implemented?

**Possible probes:**

- How do they see the reforms playing out over time?
- What factors will help/hinder efforts to improve cancer services locally?
- What is the future for the commissioning of cancer services?

### APPENDIX 3: POLICY AND EVENT TIMELINE, DECEMBER 2007 – JULY 2012

Date	Policy and Event
December 2007	Publication of the Cancer Reform Strategy Department of Health (2007) <i>Cancer Reform Strategy</i> . London: DH.
January 2009	UK economy enters into recession ONS (2009) <i>Economic and Labour Market Review</i> . London: ONS.
January 2009	Transforming Community Services Programme Department of Health (2009) <i>Transforming Community Services: Enabling New Patterns of Provision</i> . London: DH.
May 2009	The 'Nicholson Challenge' announced <i>Requirement for the NHS to deliver efficiency savings of £15–20 billion between 2011 and 2014/15</i> <a href="http://www.telegraph.co.uk/health/healthnews/5524693/NHS-chief-tells-trusts-to-make-20bn-savings.html">http://www.telegraph.co.uk/health/healthnews/5524693/NHS-chief-tells-trusts-to-make-20bn-savings.html</a> (accessed 21 November 2012).
August 2009	Quality Innovation Productivity and Prevention (QIPP) programme announced
May 2010	New coalition Government
July 2010	<i>Equity and Excellence White Paper</i> <i>[Including announcement of 45% cut in NHS management costs and 33% cut in administration costs]</i> Department of Health (2010) <i>Equity and Excellence: Liberating the NHS</i> . London: DH.
October 2010	Public Spending Review unveiled <i>[£81 billion cut from public spending over four years, including 7% cut for local councils from April 2011]</i> HM Treasury (2010) <i>Spending Review 2010</i> . London: DH.
January 2011	Requirement for clustering of PCTs announced <i>[PCTs to cluster, with a single Chief Executive and management team, as a precursor to their proposed abolition in 2013]</i> Department of Health (2011) <i>PCT Cluster Implementation Guidance</i> . London: DH.
January 2011	Publication of Improving Outcomes: A Strategy for Cancer Department of Health (2011a) <i>Improving Outcomes: A Strategy for Cancer</i> . London: DH.
April 2011	Cancer Drugs Fund launched <i>[Fund worth £200 million per year for three years to pay for cancer drugs that have not yet been approved by NICE]</i> <a href="http://webarchive.nationalarchives.gov.uk/+/www.dh.gov.uk/en/MediaCentre/Pressreleases/DH_125725">http://webarchive.nationalarchives.gov.uk/+/www.dh.gov.uk/en/MediaCentre/Pressreleases/DH_125725</a> (accessed 21 November 2012).
May 2011	Funding for cancer networks guaranteed until 2013 <a href="http://webarchive.nationalarchives.gov.uk/+/www.dh.gov.uk/en/MediaCentre/Pressreleases/DH_127035">http://webarchive.nationalarchives.gov.uk/+/www.dh.gov.uk/en/MediaCentre/Pressreleases/DH_127035</a> (accessed 21 November 2012).
March 2012	Health and Social Care Act passed through Parliament <a href="http://www.legislation.gov.uk/ukpga/2012/7/contents/enacted">http://www.legislation.gov.uk/ukpga/2012/7/contents/enacted</a> (accessed 21 November 2012).
July 2012	Proposals for Strategic Clinical Networks published NHS Commissioning Board (2012) <i>The Way Forward for Strategic Clinical Networks</i> . London: DH.

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