MEASURING UP?

THE HEALTH OF NHS CANCER SERVICES

Written by the Health Services Management Centre
at the University of Birmingham and ICF International

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CANCER RESEARCH UK

A REPORT FOR CANCER RESEARCH UK

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EXECUTIVE SUMMARY

Every two minutes someone in the UK is diagnosed with cancer. It remains one of the most devastating diseases, affecting millions of people in the UK each year. More than 331,000 people were diagnosed with cancer in 2011, and this is set to further increase.

But while cancer incidence is on the increase, our survival rates are getting better with two in four people now surviving for 10 years. This is of course a positive development, yet UK survival rates remain lower than some of the top performing countries and we must do more to ensure our cancer patients get the best care possible. A well functioning NHS, with high quality cancer services, is therefore crucial if we are to meet the future needs of our population and improve our cancer outcomes.

The NHS in England is under considerable pressure. Not only has it recently been through the biggest re-organisation in its history but the NHS has also been tasked with ensuring £20bn in efficiency savings by 2014-15. On top of this, a £30bn funding gap between 2013/14 and 2020/21 is predicted if current funding levels stay as they are. These are clearly challenging times.

It is now 18 months since the Health and Social Care Act and associated changes fully came into force, and nearly two years since Cancer Research UK published its report looking at the potential impact of the reforms on cancer services in England. Given the substantial changes that have taken place over this time, Cancer Research UK commissioned this follow up research[1] to understand the current state of cancer services.

SUMMARY OF FINDINGS

A number of perceived challenges facing cancer services were repeatedly found throughout the interviews and survey responses. These included:

- **rising demand for services and a lack of capacity to respond to this rising demand;**
- **the loss of national and local leadership and infrastructure;**
- **fragmentation of commissioning across the patient pathway;**
- **variation in the roles and responsibilities of new organisations and the need to rebuild relationships and regain expertise across the new architecture.**

The set of contextual circumstances arising from the reforms, combined with the lack of resources to provide any 'headspace' were seen as hampering efforts to develop services and improve performance. Many interviewees spoke of a hiatus, with cancer services 'standing still' for the last two to three years.

MEETING RISING DEMAND WITH LIMITED RESOURCES

Half of people diagnosed with cancer now survive their disease for at least ten years and UK cancer survival rates have doubled in the last 40 years. Though this is unquestionably a positive development, better survival rates combined with higher numbers of new patients inevitably place increased demands on the service. Though cancer and tumours is the third largest area of spend in the English NHS budget behind mental health disorders and circulatory diseases, real-term spending on cancer peaked in 2009-2010 at £5.9 billion with spend in 2012-13 reducing to £5.7 billion.

In 2013-14 alone, over 1.4 million patients in England were referred by their GP for suspected cancer. This represents a 50% increase in referrals from 2009-10. There have also been significant increases both in the number of diagnostic tests being carried out and the number of patients receiving treatment for cancer following a referral from their GP. Generally, waiting time targets have held up. However, the 62 day target (calculated as the wait from urgent referral to first treatment), has fallen to the lowest level since 2009-10 and has dropped below the standard of 85% of patients being treated within 62 days, for the first time since 2009-10, which is clearly a concern.

Our findings suggest that the impact of the financial environment is considered more of an immediate challenge for cancer services than the impact of the reforms. There is widespread concern that capacity (in relation to both clinical space and workforce) is not keeping up with current demands, and that this would ultimately affect patients.

Recommendations

1. The Government should increase investment in cancer services, to ensure the NHS can meet rising demand and ensure our cancer outcomes become the best in the world. Investment is particularly crucial in diagnostic services, where rising demand is starting to outstrip the resources available.

SYSTEM LEADERSHIP AND COMMISSIONING

The major changes that have taken place in the structure of the NHS in England have led to a vacuum at a national level in terms of the leadership and support needed to drive the cancer agenda. The loss of the previous national infrastructure such as the National Cancer Action Team is reported as making people's day-to-day jobs more difficult, and hampering their ability to create enough 'headspace' to think through the inevitable reforms to cancer services that will be required for the future. The lack of basic support and resources for leading strategic developments is also raised as a key issue at the local level. The disbanding of dedicated cancer networks is seen as particularly problematic.

The roles and responsibilities of the new NHS organisations are generally not well understood, leading to concerns around fragmentation in the commissioning of a patient pathway between different bodies. There was generally support for role of specialist commissioning of many cancer services. However, the complexity of local and specialist commissioning is seen as confusing and hampering efforts to take a 'whole pathway' approach to service redesign. There is genuine confusion over who is accountable for decision making within the system.

Recommendations

2. The Department of Health should create a recognised cancer leadership team to provide support and strategic oversight to NHS England, Public Health England and the Department. Building on the work of the National Clinical Director for Cancer in NHS England, a similar lead role should be created at Public Health England, with a cancer lead at the Department of Health given clear responsibility for strategic oversight.

3. The Department of Health should review Improving Outcomes: a Strategy for Cancer in light of the changes to the NHS structures and update it as appropriate to ensure it is fit for purpose for the new commissioning system. The Department should make a concerted effort to communicate the relevance of the Strategy to the new commissioning system.

4. NHS England should provide greater support and funding to the Clinical Reference Groups to enable them to achieve their potential for system development and ensure they drive real improvements.

5. The Department of Health, NHS England and Public Health England must urgently clarify and communicate the responsibilities of the different commissioners of cancer services. Strategic Clinical Networks should map out commissioning responsibilities for their geographical area and ensure commissioning organisations are working together to provide coordinated cancer services.

SERVICE DEVELOPMENT AND IMPROVEMENT

Interviewees and survey respondents consistently referred to the inability, at both a national and local level, to create the necessary 'headspace' to think strategically about service developments and improvements. Follow-up care, survivorship and personalised medicine were considered important areas to focus on for the future, with an acknowledgement that current models of care were too reliant on secondary care. Though there was enthusiasm and motivation to make improvements, and a willingness to be innovative, the practical barriers were seen as limiting factors.

Funding, capacity and poor coordination were all issues raised as barriers to the development of cancer services, as were the way the NHS market operates and vested professional interests. Interviewees suggested that better integration of care between secondary and primary care, or shared care arrangements, are needed. This requires a fundamental shift in the role of primary care in treating cancer patients and survivors which in turn will necessitate investment in capacity, training and development. Further work also needs to be done in prevention and early diagnosis.

The effective use of existing data and knowledge will underpin service development and improvement for the future. But though there was much praise for the wealth of cancer data available

there was significant concern that the capacity and capability to maximise the potential of this data was not apparent.

Recommendations

6. The Department of Health and NHS England should explore longer-term budgeting arrangements to allow commissioners the flexibility to invest and innovate. For example, CCGs could be allowed to carry a percentage of their budget over a three-year period to allow genuine outcomes-based commissioning rather than short-term contracting, and time for long-term cost savings to be realised.

7. Commissioners at a national and local level should work together to make realistic long-term plans to meet demand for cancer services, taking account of future expected developments such as longer-term care and personalised medicine. CCGs and other local commissioning bodies should actively seek opportunities for greater collaboration, for example through co-commissioning or lead commissioner models.

8. The Department of Health, NHS England and Public Health England should ensure they truly harness the power of data to drive improvements in cancer care. Investment should be made in the capacity and capability to collect and analyse data effectively and in real time, to realise the opportunity that data gives and ensure the NHS matches outcomes of the best countries in the world.

[1] A range of methods were employed to undertake the study including: the interrogation of national data sets to determine trends in service performance such as cancer waiting times, diagnostic waiting times and cancer expenditure; 45 in-depth interviews with a wide range of participants including policymakers, cancer clinicians, commissioners, GPs, and Public Health experts; and a survey distributed through professional networks and associations which generated 465 responses.

INTRODUCTION

Cancer affects the lives of millions of people in the UK. Cancer cases continue to rise, with around a third of a million people diagnosed every year in the UK in 2011 (Cancer Research UK, 2014). Over the last 40 years there have been major improvements in cancer care and now half of people diagnosed with cancer in the UK will survive for at least ten years (Cancer Research UK, 2014).

However, while cancer outcomes have improved in the UK, survival rates vary significantly between cancer types and cancer outcomes in the UK still lag behind other developed countries in some regards. Better awareness of the causes of cancer can make a major contribution to increasing survival - more than four in 10 cancers could be prevented by lifestyle changes. Early diagnosis of cancer is crucial to improving prospects of long-term survival (Cancer Research UK, 2014).

New, more effective treatments are continuously being developed, with research finding ways to refine current treatments or discovering new treatments that can improve patient outcomes. But the best quality care is still not being delivered consistently across the country. There is still much to do to ensure that everyone receives the best cancer care possible. Ensuring that NHS cancer services are the best they can be, so that even more people survive cancer, therefore remains a priority.

In November 2012, Cancer Research UK published a report, Cancer Services: Reverse, Pause or Progress? which examined the potential impact of the Health and Social Care Act and financial constraints on cancer services in England. At the time of that study, the structures and arrangements for the planning and commissioning of cancer services were still to be fully agreed. However, the report noted genuine concerns about the future for cancer services given the uncertainty and disruption caused by widespread system change.

The reforms associated with Health and Social Care Act came into force on 1st April 2013, resulting in extensive changes to the NHS architecture. NHS England has been established with responsibility for commissioning specialised services and primary care services – supported by four regional offices and 27 local area teams. Seventy-four Clinical Reference Groups (CRGs) have been set up to provide NHS England with clinical advice for the full range of specialised services that it directly commissions. Strategic Health Authorities and Primary Care Trusts have been replaced by Clinical Commissioning Groups (CCGs) - groups of GPs who are responsible for local commissioning of healthcare services, and who are supported by Commissioning Support Units (CSUs).

Public health services have been moved into local authorities and a new executive agency, Public Health England, has been created incorporating the Health Protection Agency. Health and Wellbeing boards have been established within local authorities to join up the commissioning of healthcare by CCGs with the commissioning of social care and public health improvement, while a national system of HealthWatch bodies has been established to replace Local Involvement Networks as the formal mechanism for patient and public involvement in NHS services.

Though these changes have largely affected the commissioning functions of the NHS, the provider side has not been immune to change, for it was also a requirement of the Act that the 114 NHS Non-Foundation Trust organisations in place at the time were to achieve Foundation Trust status by 2013-14. This has not subsequently been achieved.

Evidence shows that disruption is caused before, during, and after large-scale change and studies suggest that any positive effects of reorganisation may take some time to be achieved - an organisation's performance takes anywhere between 18 months and three years to return to pre-change levels (Fulop et al, 2002, Andrews and Boyne, 2012). An assessment of how cancer services are currently performing, looking at the longer-term impact of the Act and its associated changes, and drive for efficiency savings is therefore a worthwhile undertaking at this point in time.

Since Cancer Research UK's previous report was published, activity levels in cancer services have continued to rise. Performance against waiting time targets is generally holding up but starting to show some signs of stress in the system. For example, the 62 day targets were falling quite

significantly by the end of 2013-14, resulting in the first breach of its 85% standard for the first time.

In real terms, the NHS budget in England is smaller now and the financial situation is increasingly seen as a cause for concern (King's Fund, 2014). It was noted previously that responding to the challenge of £20bn efficiency savings in the NHS by 2015 would require radical changes to the design and delivery of services and patient care pathways, rather than short-term fixes or the identification of 'quick wins'. The imperative was to ensure that all parts of the system worked together to bring about lasting improvements in the quality and outcomes of care. This point in particular needs to be explored now that the new architecture has had a reasonable amount of time to bed in.

Cancer Research UK therefore commissioned an independent research team from the University of Birmingham's Health Services Management Centre and Consultancy firm ICF GHK to build on the 2012 report and to explore the current state of cancer services in England. This evaluation focuses on:

- **Whether cancer services are improving, deteriorating or at a stand still**
- **Whether the concerns and doubts raised by Cancer Research UK's earlier report are being confirmed or disproved**
- **How leadership and accountability are evolving within the new system**
- **The effectiveness of the new commissioning architect**

The evaluation synthesises data from three sources – a quantitative analysis of key indicators, and qualitative analysis through a series of interviews, complemented by an online survey.

An analysis of trends in cancer waiting times and diagnostic waiting times spans an eight year period from April 2006 to March 2014, which covers the time during which the Health and Social Care Bill passed through Parliament, associated reforms were introduced and local implementation began. Trends in expenditure on cancer services over the same period are also analysed, using Department of Health programme budget data[2]. Calculations of programme budgeting expenditure data are complex and rely on assimilation of activity and cost data from a range of sources. As such, the figures provided within this report should be seen as best estimates rather than exact values.

Qualitative research was undertaken to explore the views and experiences of cancer experts at a national level and from NHS staff in five case study sites, determined by the boundaries of NHS England Local Area Teams. Forty-five in-depth interviews in total were carried out between April and June 2014 with a wide range of participants including policymakers, service providers – both clinicians and managers, commissioners –Clinical Commissioning Groups (CCG) and Commissioning Support Units, Area Teams (the regional bodies of NHS England), Clinical Network and Clinical Senate staff, GPs, Public Health experts and patient representatives. In order to ensure anonymity, quotations from the interviews have been attributed using only the interviewee's role.

To complement the in-depth insights gleaned through the qualitative interviews, an online survey was conducted to assess a broader range of views on cancer services. The survey gathered quantitative evidence using fixed response questions but also contained two open ended questions for free text responses. It was distributed to direct contacts of the research team and Cancer Research UK, through the memberships of several professional networks and organisations, and to a named individual in each CCG, Area Team and Local Medical Committee. To achieve a wide reach, a 'snowballing' approach was employed, with recipients encouraged to share the survey link with their colleagues and contacts. This approach resulted in a total of 465 responses.

Further details about the research methodology can be found in Appendix 1.

[2] Since 2003, the Department of Health has collected expenditure data categorised by clinical speciality or health area programme budgeting.

MEETING RISING DEMAND WITH LIMITED RESOURCES

All areas of public services have felt the increasing pressure of responding to demand within tightening financial constraints. The Chancellor George Osborne's first spending review, in 2010 resulted in a budget reduction averaging 19% across all departments, except for the NHS, and Overseas Aid, which were protected (HM Treasury, 2010). In addition, a further £11.5bn savings are to be made from government departments in 2015-16 (HM Treasury, 2013).

Fortunately, the budget for the NHS will continue to be 'ring-fenced' in recognition of its central importance to people's lives. However, this concession is nonetheless given within a context of increasing demand for services as a result of an expanding and increasingly older population.

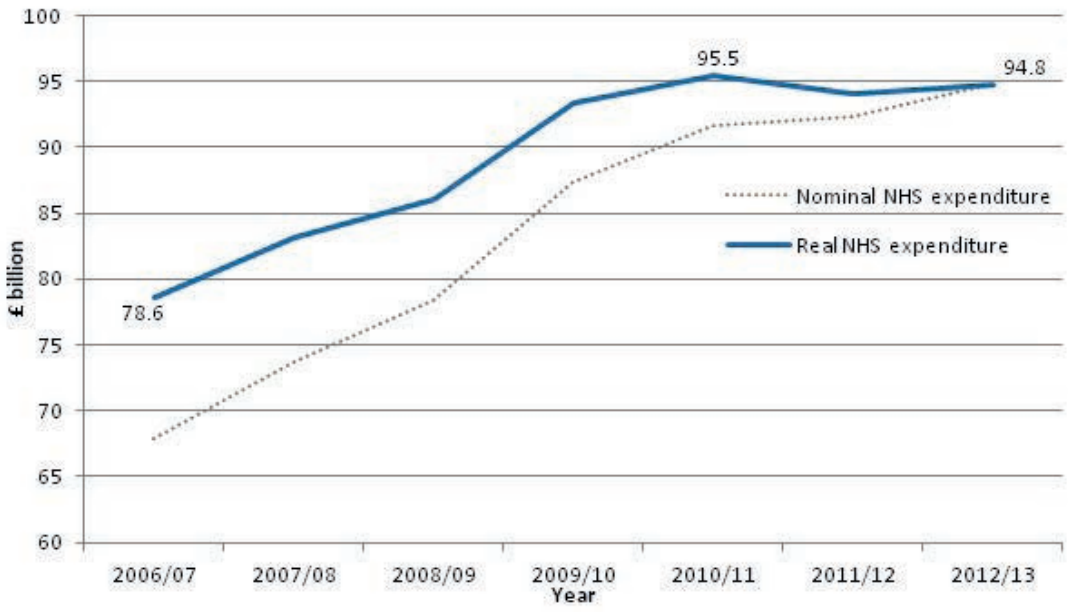
As set out in this section, demand on cancer services has continued to increase at all stages of the patient pathway. Over 1.4 million patients in England were referred by their GP for suspected cancer in 2013-14. Though the number of people being cared for continues to increase and shows no signs of abating, the cancer budget has essentially flat-lined. It is therefore important to assess how cancer services are coping, within this context.

EXPENDITURE ON CANCER SERVICES

Over the period 2006-07 to 2012-13, there had been a general increase in total spending on the NHS in England. In nominal terms (the amount of money spent each year), spending had increased by 40% from £69.7 billion to £94.8 billion. When the spending is calculated in real terms however (using GDP deflators published by the Treasury), the increase was just 21% over the seven year period – from £78.6 billion to £94.8 billion (Figure 1).

Real terms calculations were made using 2012/13 values (inflating previous values to 2012/13 price levels, using HM Treasury GDP deflators)

Figure 1: Real and nominal spending in the NHS in England, 2006-07 to 2012-13

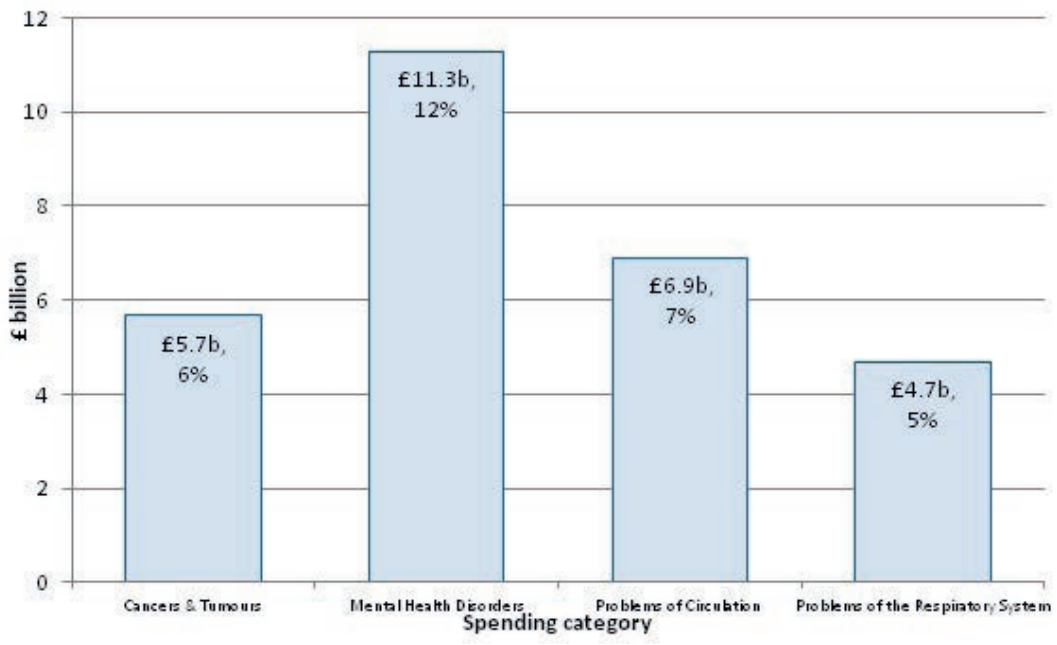


Source: NHS England: Programme Budgeting data, 2012-13

In 2012-13, spending on cancer and tumours was £5.7 billion, or 6% of the total English NHS budget (Figure 2). This was the third largest category of spending behind mental health disorders and circulatory problems (excluding the category "other areas of spend/condition"). Indeed, cancers and tumours has been the third largest category of spending every year between 2006-07 and 2012-13, and has represented between 6% and 6.5% of the total NHS budget.

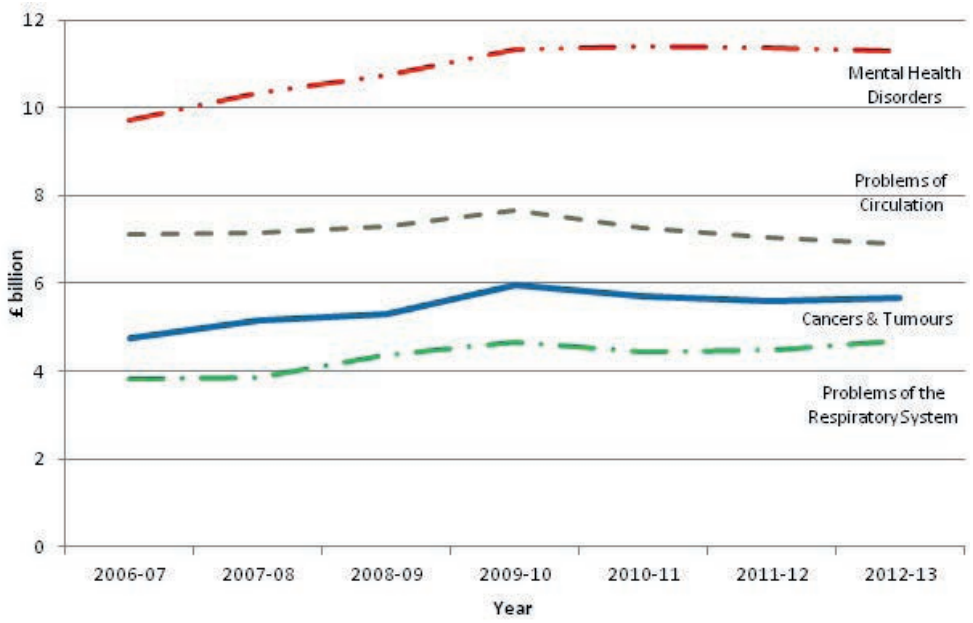
Real term spending on cancer and tumours peaked in 2009-10 at £5.9 billion in England. In the two following years to 2011-12 there was a real term decrease of 6%, before a slight increase to reach £5.7 billion in 2012-13. Looking at other areas of expenditure for comparison, real term spending on mental health disorders has plateaued since 2009-10, whilst real term spending on circulatory problems has fallen every year since 2009-10 (a total decrease of 10% between 2009-10 and 2012-13). Spending on respiratory problems – the next largest area of expenditure – has remained fairly constant between 2009-10 and 2012-13 (Figure 3).

Figure 2: Spending in the English NHS on four categories, 2012-13



Source: NHS England: Programme Budgeting data, 2012-13

Figure 3: Spending in the NHS in England on four categories, 2006-07 to 2012-13



Source: NHS England: Programme Budgeting data, 2012-13

RESOURCES TO TACKLE EXISTING WORKLOADS

Interviewees raised a number of issues related to the impact of constrained resources on existing workloads. Examples were given of delays in replacing staff, some of which were lengthy, impacting heavily on other staff who were expected to pick up additional work in the interim. This was the case for both medical roles – such as consultant posts, and nursing posts – such as cancer nurse specialists. The latter were singled out as being a soft target when it came to making cost savings.

> "We're constantly being asked to prove what the impact of specialist nurses are, it's an easy area to cut."
> – National Interviewee

There was an acknowledged tension between increasing referrals in order to maximise the benefits of earlier diagnosis and the resultant increasing activity and costs. In an environment where CCGs may be trying to exhibit financial prudence, this is a somewhat counterintuitive approach, as a number of interviewees noted.

> "So ...we're trying to get people diagnosed earlier which means an increased referral rate from primary care. You've got to increase referral rates to get people in at an early stage of disease. The CCG mantra is exactly opposite of that. You have to reduce your referral rate."
> – National Interviewee

There appeared to be widespread concern that diagnostic capacity was not keeping up with current demands. In addition to the clear increases in activity, patient pathways are becoming increasingly complex with new and more effective diagnostic tests possible in order to achieve a better diagnosis to inform treatment plans. However, one interviewee subsequently noted the need for pathways to be systematically reviewed in order to ensure that any new tests used were substitutes and not additions.

Physical capacity to provide treatment was another area of concern, as expressed in stark terms by one interviewee in relation to the ability to treat increasing numbers of patients with chemotherapy.

> ''Key issues would be bed capacity and day case chair capacity... over the last four years for instance, our day case activity in Haematology has gone up by 38% and in Oncology it's been 24% and yet our chair capacity and nursing capacity within those units have remained the same.''
> - Service Manager, Acute Trust

The ability to cope with increasing demand in this way suggests that some organisations at least have found ways to increase their productivity and deliver services more efficiently.

And the effect of cost pressures leading to a stronger focus on productivity and the tackling of variation in practice, in order to deliver efficiency savings, was raised specifically as a positive consequence by interviewees.

> ''PCTs were often quite cautious in challenging providers because there were lots of processes to go through, and the individual managers were dependent upon the local health economy for their employment... GPs don't rely upon CCGs for their income, and therefore are bolder in their ability to say, this is what we want.'' - Network Manager

> "... there is without doubt much more scrutiny of people, of GPs' use of resources, secondary care resources particularly...It's aided by the National Cancer Intelligence Network and the availability of cancer practice profiles, but the ability of GP cancer leads to show to practices how they compare to other practices in their use of service, in their referral patterns, I think has been a good thing...I think to date [the data] has been used primarily to improve quality and that's been a good thing."
> – National Interviewee

However, there was also a sense that the 'low hanging fruit' of efficiency savings has already been picked and there is nowhere else to go.

> ''So we're doing a lot of process-mapping work ... What does really good look like and what does achievable look like and what does that mean in terms of taking money out of the system?' But this 'low hanging fruit' has now all been harvested and they have only made half of the necessary savings... All the stuff along the lines of,

> ''Change your ways of working, look around you at your peers, how do they deliver their services? Could we do that any better?' – We've already done all of that.''
> - Cancer Services Manager, Acute Trust

The financial situation also means that while providers may be keeping their heads above water, they are unable to invest resources to make any improvements in services.

> ''...effectively what we need to be able to do is to be able to reinvest a small amount of that saveable contribution that we're making into the organisation's bottom line, back into improving our bed capacity, nursing capacity and chair capacity... we're talking about £2million worth of capital investment.''
> - Service Manager, Acute Trust

There appears therefore to be a tipping point when efficiency savings have all been achieved but financial constraints begin to impinge on the ability to provide optimum care. For example, in the above interviewee's Trust, a lack of capacity means that cancer patients now have to be treated on non-Cancer wards. This in turn means potentially less efficient working arrangements as staff move between wards, and concerns that less than optimum care is being given.

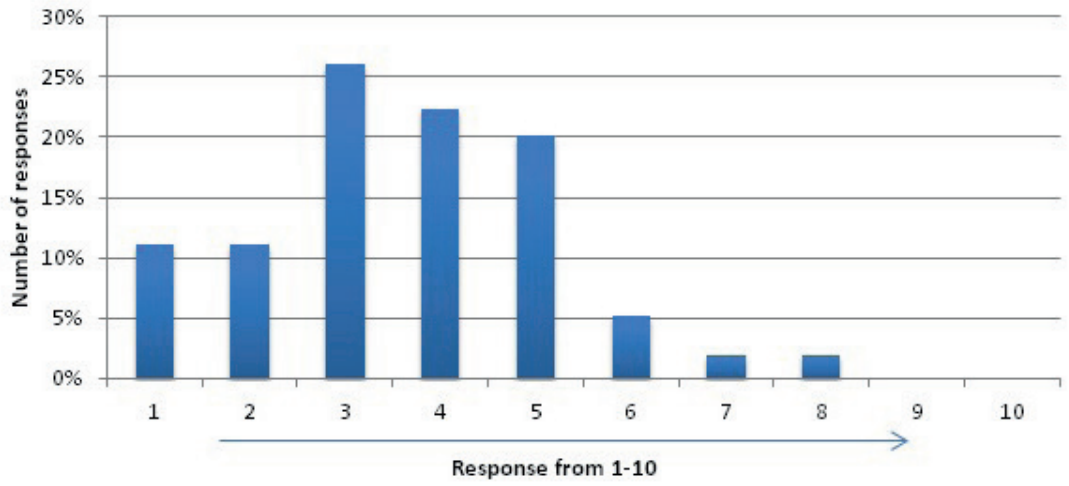
LOCAL AUTHORITIES AND PUBLIC HEALTH

In general, interviewees were not confident that prevention and early diagnosis of cancer were being prioritised or that the appropriate resourcing was in place. Public Health budgets were ring-fenced when teams moved into Local Authorities (LAs). However, there is a growing unease that budgets for this activity will become increasingly squeezed. Local Authorities are under increasing financial pressure and many are facing severe cuts to services in order to balance the books. Interviewees felt that this situation was bound to influence the prioritisation given to public health and health prevention. Interviewees commented that they were concerned about 'scope creep' within Public Health, with teams being expected to take on responsibility for a range of additional services, such as leisure services, that LAs felt could be justifiably badged as public health activities. This would lead to 'massaging' of the ring-fenced Public Health budget so that teams were expected to deliver a wider range of services with the same resources. In addition, some Public Health teams have lost staff as a result of the transition to Local Authorities, losing valuable skills and experience as well as vital capacity.

PERCEPTIONS OF FINANCIAL CONSTRAINTS

Survey respondents were asked to rate the extent to which they thought the current financial environment had affected the delivery of frontline patient care. Answers were provided on a 1-10 point scale, with a rating of 1 for 'very negative impact', rating of 10 for 'very positive impact and 5 for 'neutral impact'. Seventy-one per cent of respondents rated the impact 1-4 (negative), 20% rated 5 (neutral) and 9% rating 6-8 (positive). There were no responses with an assessment of 9 or 10. The average rating for this question was 3.6 (Figure 4).

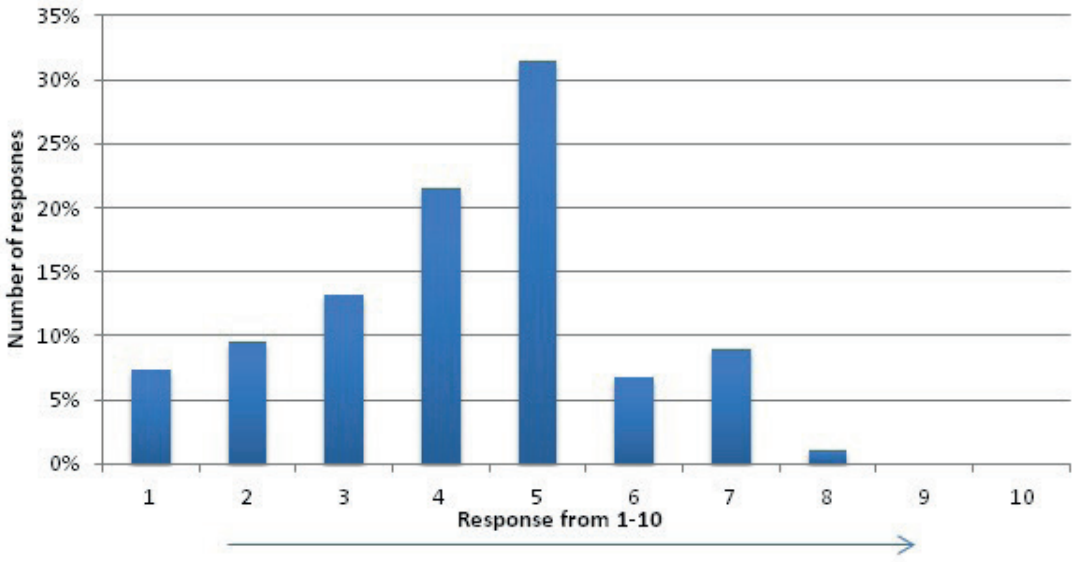
Figure 4: To what extent is the current financial environment affecting the delivery of frontline patient care?



Source: University of Birmingham Health Services Management Centre and ICF International survey data

Survey respondents were then asked to rate the impact of the recent NHS reforms, both on cancer services generally, and patient experiences of cancer care using the same ten point scale. Overall responses suggest that – a year on from the health reforms coming into effect – their impact is considered to be relatively neutral with an average rating of 4.2 for impact on cancer services and 4.5 for impact on patients' experience of care. However, only 17% of respondents considered that the reforms have had a positive impact on cancer services, and similarly only 16% on patient experiences' of care (Figure 5 and 6).

Figure 5: On balance, what impact (if any) have the recent NHS reforms had on cancer services in your area:

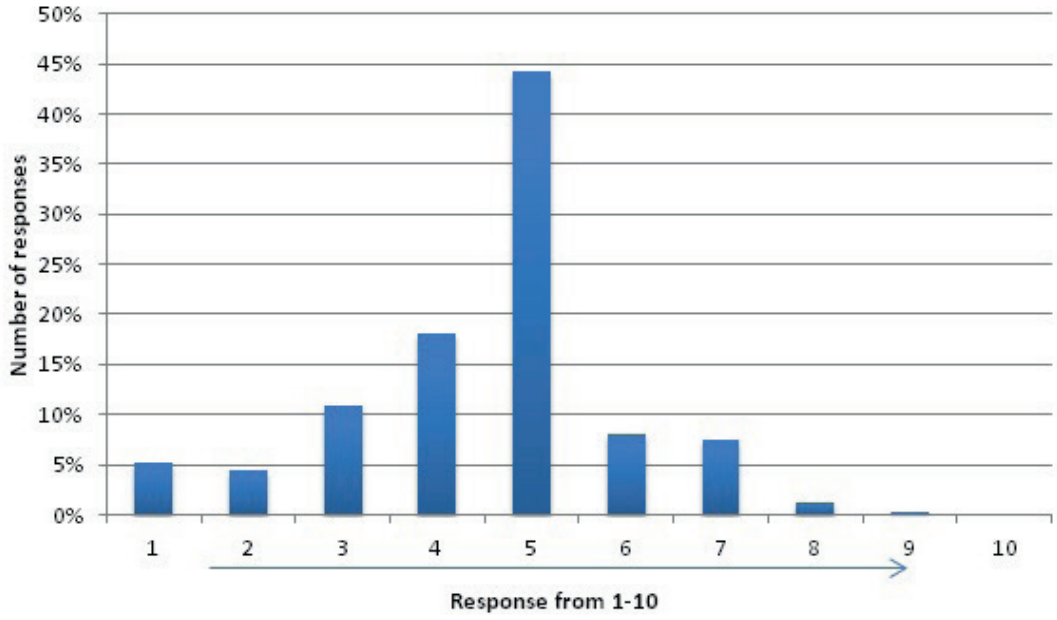


Source: University of Birmingham Health Services Management Centre and ICF International survey data

When asked about the impact the reforms and efficiency savings might have had on patients, interviewees were generally of the view that this would have been minimal to date, as the parts of the system that were patient-facing had not been as destabilised by the reforms, as the commissioning functions.

> ''Well, because the Primary Care providers and the Trust providers have largely remained stable – you know they've been the least affected I suppose if you want to look at it that way. The people go to see their GP. They get referred on to the specialist hopefully and that relationship is stable and it works in the main and it hasn't been disrupted yet.'' – Public Health specialist

Figure 6: On balance, what impact (if any) have the recent NHS reforms had on patients' experiences of cancer care in your area:



Source: University of Birmingham Health Services Management Centre and ICF International survey data

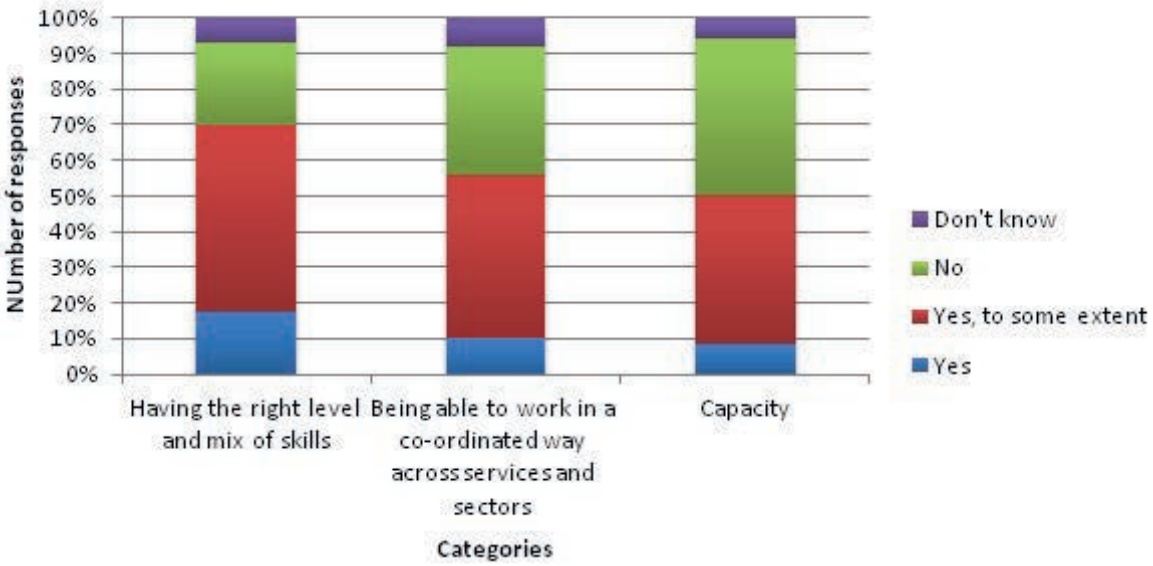
However, there were concerns that it was becoming harder to manage demand.

> "Current staffing levels mean we are unable to provide as comprehensive a service as could be to everyone at every stage." - Allied Health Professional

> "We need to have more capacity as we are seeing more patients and surgery and treatments are becoming more complex, yet we are trying to fit more patients into the already squeezed resources that we have ..." - Doctor, cancer specialist

Survey respondents were not entirely optimistic that the right workforce is in place to deliver high quality cancer care (Figure 7).

Figure 7: Do services have the right workforce to deliver high quality cancer care, in terms of:



Source: University of Birmingham Health Services Management Centre and ICF International survey data

CANCER WAITING TIMES

Cancer waiting times give an indication of how well the system is coping with demand. Three main targets are routinely monitored and reported against, as shown in the diagram below (Figure 8).

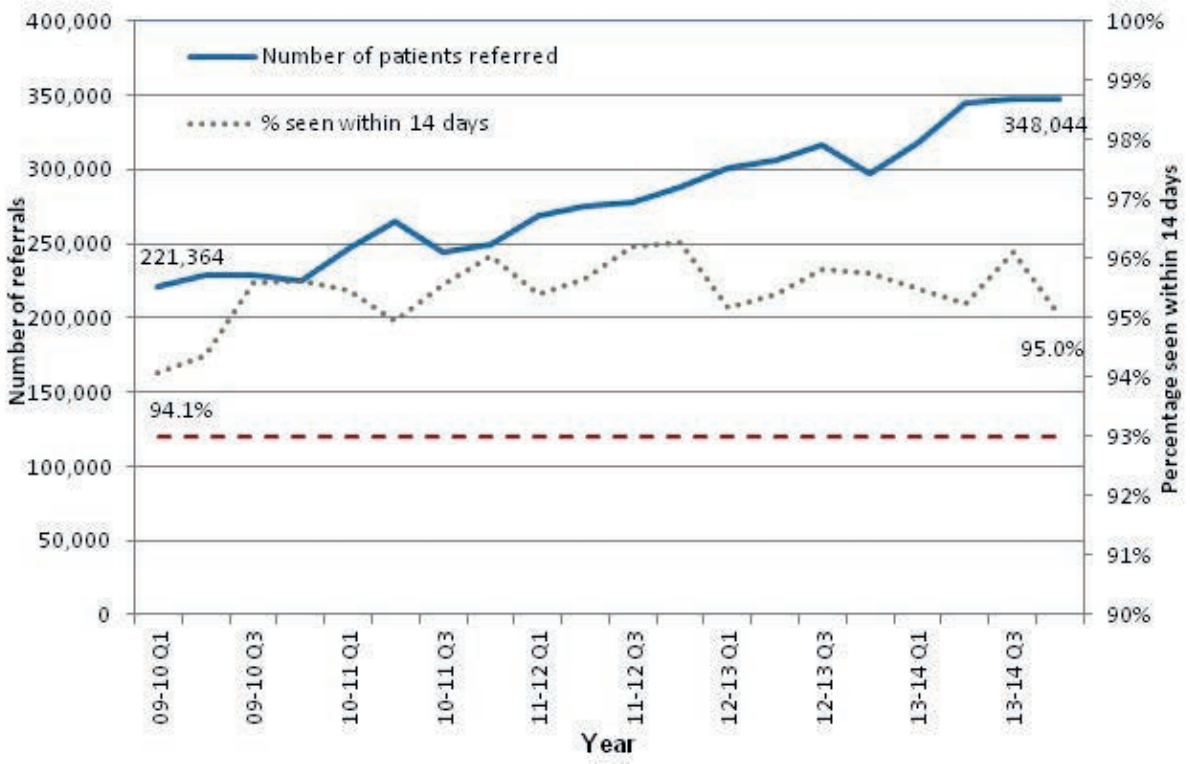
- The 14 day wait from urgent referral for suspected cancer from a GP to first appointment with a specialist, with a standard of 93% of patients applied to this target.
- The 62 day wait from an urgent referral to first treatment, with a standard of 85% of patients applied to this target.
- The 31 days wait between when a decision is made to undergo treatment to the first treatment, with a standard of 96% of patients applied to this target.

Figure 8: Cancer waiting time targets in England in relation to the patient pathway

14 DAY TARGETS

The number of patients in England receiving an urgent referral from their GP for suspected cancer has increased dramatically since 2009-10 (see Figure 9). There were just over 220,000 urgent GP referrals in Quarter 1 (Q1) 2009-10; by Quarter 4 (Q4) 2013-14 this had risen to just under 350,000. When comparing complete years, in order to remove seasonal variation, there has been an increase in the number of urgent GP referrals for suspected cancer from 900,000 in 2009-10 to over 1.4 million in 2013-14. This represents an increase of over 50%.

Figure 9: Total number of urgent GP referrals in England, and the percentage seen within 14 days, 2009-10 to 2013-14



Source: Cancer Waiting Times Statistics, Department of Health, 2009-10 Q1 to 2013-2014)

Despite the large increase in the number of urgent GP referrals for suspected cancers, the percentage of patients who are seen by a specialist within 14 days has remained relatively constant. Since the beginning of 2009-10, the percentage of patients in England seen within 14 days of an urgent GP referral has consistently been above 94%, with a peak of 96.3% in Q4 2011-2012 (Figure 9), and in the most recent 12 month period the average was 96%. However, it should be noted that the percentage of providers achieving the target has decreased over the past two quarters, from 99% to 94% which suggests increasing variation in performance between providers.

These large increases in the number of urgent referrals can only partially be explained by population changes. Over the time period analysed, there has been an increase in the number of people living in England and the population is becoming older. However, the population in England only increased by 2% between 2009 and 2012, meaning the number of urgent referrals per 100,000 of the population grew from 1,732 in 2006-07 to 2,525 in 2013-14,[3] an increase of 46%.

The number of patients in England who are subsequently diagnosed and treated for cancer following an urgent GP referral has also increased from just under 24,000 in Q1 2009-10, to just under 31,000 in Q4 2013-14 (Figure 10). However, the rate is lower than the rate of increase in the number of urgent GP referrals. This means that the percentage of urgent GP referrals which result in a diagnosis of and treatment for cancer has decreased. In 2009-10, 11% of all urgent GP referrals resulted in a diagnosis of and treatment for cancer, whereas in 2013-14 this has fallen to 9%. This is not necessarily a sign of the system not working, but actually reflects greater numbers of patients referred on the two week wait pathway by GPs.

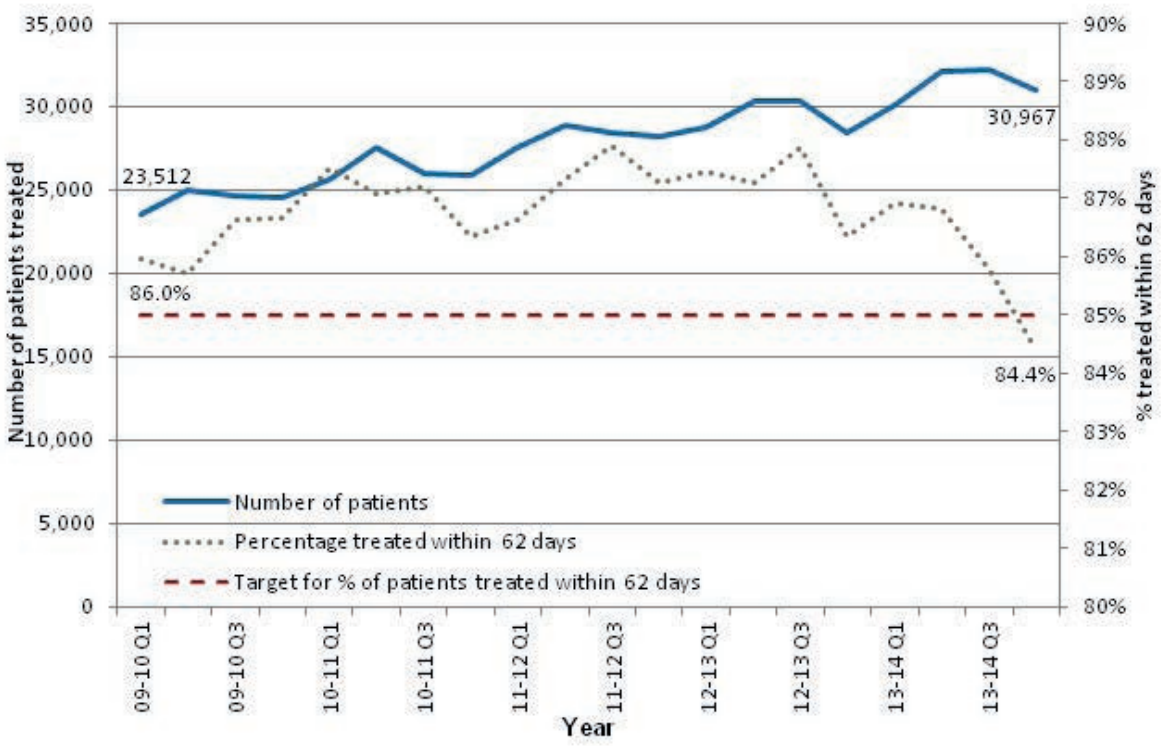
[3] Using 2013 population estimates from the Office for National Statistics (2014), 2012-based Subnational Population Projections.

62 DAY TARGETS

The percentage of patients in England who begin treatment within 62 days of an urgent GP referral increased between 2009-10 and Q3 2012-13, where it peaked at 87.9%. However, since Q3 2012-13, performance against the 62 day target has begun to decline. By Q4 2013-14, 84.4% of patients began treatment within 62 days, the lowest proportion in the period analysed and the first breach of the 85% standard (Figure 10).

Meanwhile, the number of providers able to achieve the standard has decreased significantly - in Q1 2009-10 85% of providers met the target. However, by Q4 2013-14, only 61% of providers were achieving 85% or more – the lowest level in the period analysed. Therefore, some providers are struggling far more than others to meet their 62 day targets.

Figure 10: Total number and percentage of patients treated within 62 days in England, 2009-10 Q1 to 2013-14 Q4



Source: Cancer Waiting Times Statistics, Department of Health, 2009-10 Q1 to 2013-14 Q4.

31 DAY TARGETS

The 31 day diagnosis to treatment target includes patients from all referral routes, not just those referred by their GP on the two week wait. The percentage of patients receiving treatment within 31 days of diagnosis in England has remained constant since 2009-10, at between 98.0% and 98.5%.

PERFORMANCE MANAGEMENT BY TARGETS

Several interviewees commented on the performance management of providers against the waiting time targets. There was a general acknowledgment that the 62 day wait target was slipping but many interviewees talked about the need for the target to be realistic. Interviewees noted that with increasingly complex pathways and more diagnostic tests, a blanket target for all tumours was not a particularly helpful means of measuring performance. Instead they suggested that different tumour groups might be better monitored against a more meaningful target for that specific pathway. Some specific reasons for the slippage were provided by interviewees. These included handovers between secondary and tertiary care providers leading to delays while patient information was transferred, and certain pathways specifically requiring a 'halt' or period of time to elapse between procedures i.e. prostate cancer and the healing time necessary for a patient between a biopsy and an MRI scan.

Some survey respondents also expressed the view that the emphasis on national performance targets is at the expense of quality of care, suggesting that this 'top down' strategy for improving services may need to be re-thought:

"The targets of treatment times do not always provide good care and may well reduce outcomes." - Oral Surgeon

"Too many targets and plans come down from on high. It would be nice if the frontline staff could have some say in how to improve their patients' care." - Doctor, cancer specialist

"Managers are obsessed with targets and not quality." - Doctor, cancer specialist

DIAGNOSTIC TESTS WAITING TIMES

Diagnostic activity and waiting times in England have been reported in a consistent way since January 2006 onwards. In January 2006, nearly 816,000 diagnostic tests were carried out, with this rising to 1.6 million by March 2014. The data for diagnostic tests is broken down by the type of test, with data for 15 different tests reported on a monthly basis. Not all of the tests reported on are directly related to cancer. The tests which are related to, but not exclusive to cancer are: MRI, CT, non-obstetric ultrasound, colonoscopy, flexi sigmoidoscopy, cystoscopy, gastroscopy and barium enema. This analysis focuses on the first seven of these tests, though the figures presented are for all conditions, as cancer activity alone is not easy to separate out. Barium enema has not been included in the analysis presented here as recent evidence suggests it is likely to be phased out.

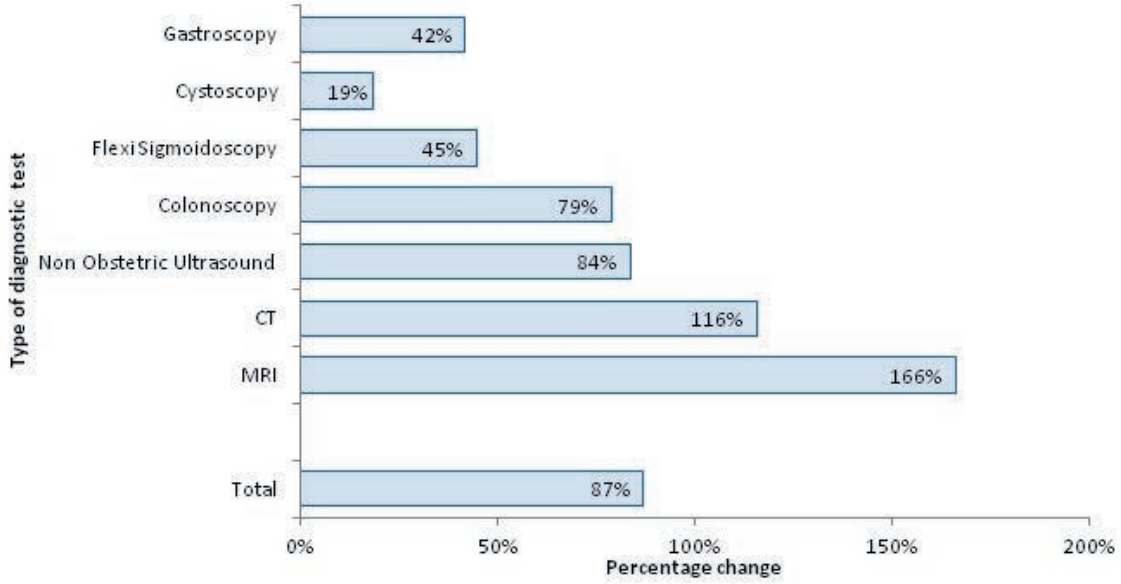
For these seven tests, activity levels have increased substantially in England between 2006-07 and 2013-14. The largest increase has been in MRI and CT scan tests, with smaller increases in cystoscopy tests (Table 1 and Figure 11).

Table 1: Average number of tests carried out per month in England, 2006-07 to 2013-14

Test	06-07	07-08	08-09	09-10	10-11	11-12	12-13	13-14
MRI	83,423	113,342	137,050	157,987	169,620	182,709	200,620	222,176
CT	165,335	206,495	234,780	259,456	278,279	301,212	330,509	357,025
Non-Obstetric Ultrasound	286,494	341,720	383,859	422,802	446,132	466,003	493,232	526,074
Colonoscopy	18,684	21,799	24,345	26,305	27,036	30,037	33,303	33,413
Flexi Sigmoidoscopy	13,170	14,615	15,227	16,445	16,705	18,147	19,390	19,061
Cystoscopy	20,789	23,876	24,799	25,443	25,576	26,035	24,166	24,657
Gastroscopy	34,446	38,317	40,748	42,959	42,785	44,326	46,491	48,843
Total	**622,341**	**760,164**	**860,808**	**951,397**	**1,006,133**	**1,068,469**	**1,147,711**	**1,231,249**

Source: NHS England, Monthly Diagnostic Waiting Times and Activity, 2006 to 2014

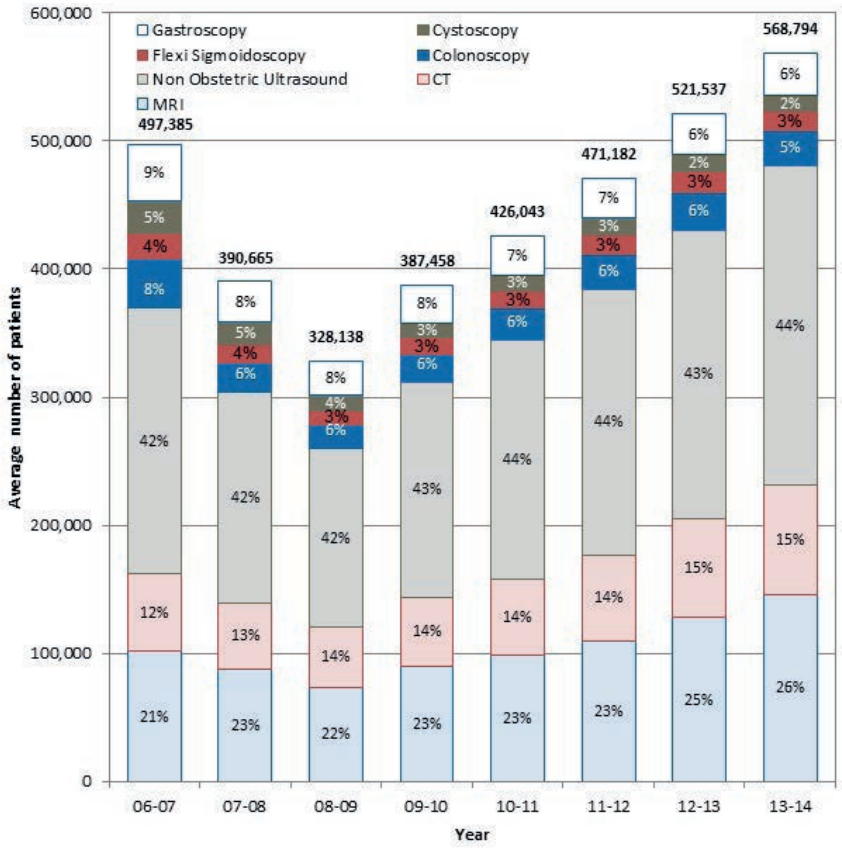
Figure 11: Change in the average number of diagnostic tests carried out per month in England, 2006-07 to 2013-14



Source: NHS England, Monthly Diagnostic Waiting Times and Activity, 2006 to 2014

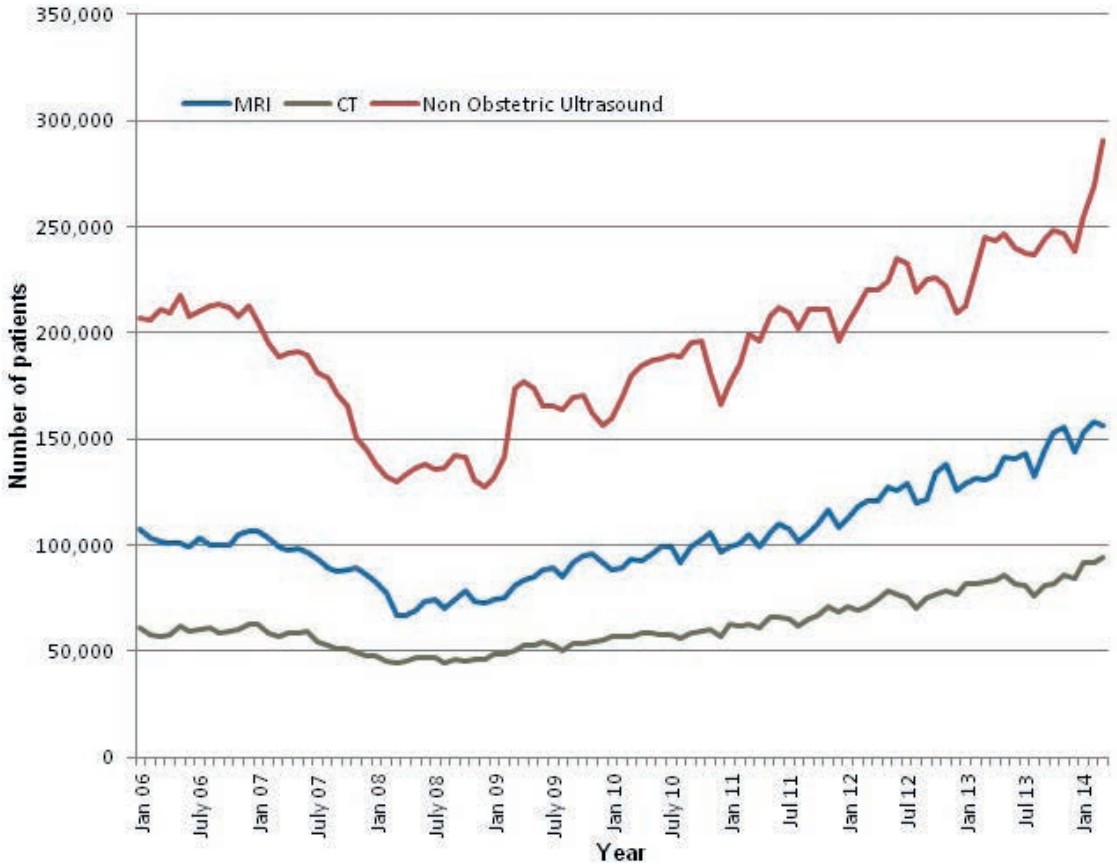
The average number of patients in England on a waiting list for a diagnostic test at the end of each month has varied significantly between 2006-07 and 2013-14 (Figure 12). From 2006-07 to 2008-09, there was a 34% decrease in the number of patients on a waiting list, from an average of just over 497,000 in 2006-07 to 328,000 in 2008-09. However, since 2009-10 the average number of patients on a waiting list per month has steadily risen to 569,000 in 2013-14 – an increase of 73% since 2009-10, and of 14% since 2006-07. Most of the patients on the waiting list were waiting for an imaging test (MRI, CT scan and non-obstetric ultrasound). This is not unexpected, given the increase in the number of diagnostic tests being carried out, as seen in Figures 13, 14 and 15.

Figure 12: Waiting lists by type of test in England, 2006-07 to 2013-14



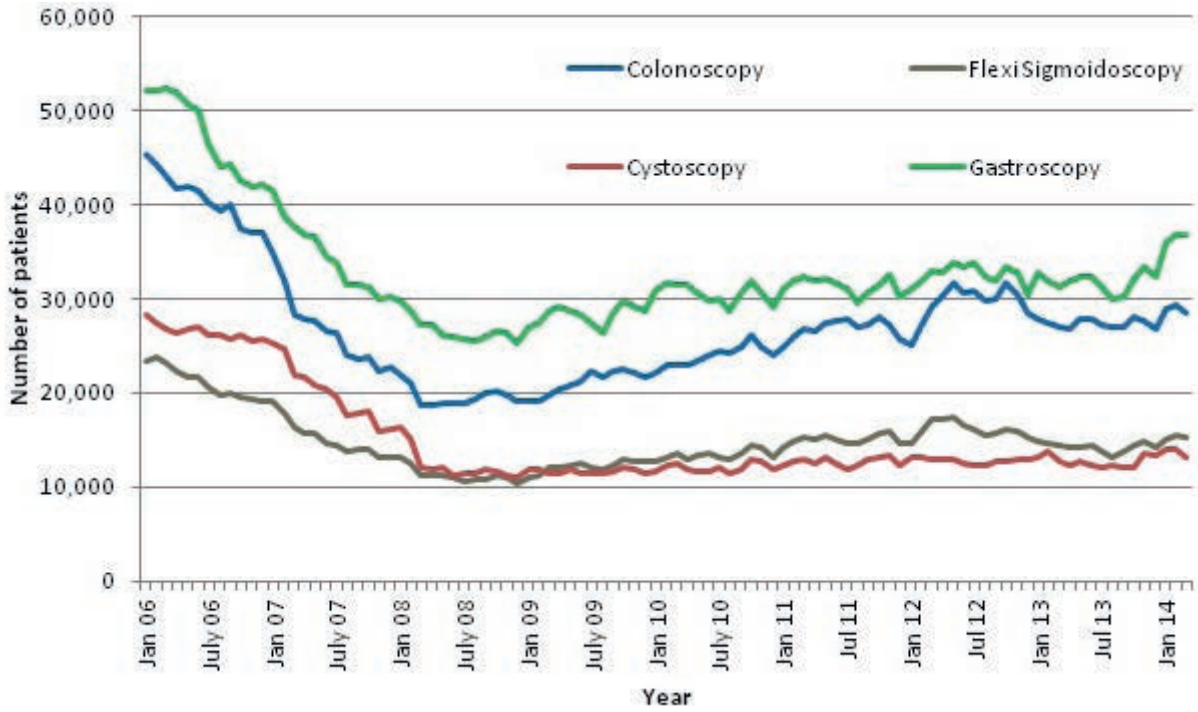
Source: NHS England, Monthly Diagnostic Waiting Times and Activity, 2006 to 2014

Figure 13: Number of patients on the waiting list at the end of month in England, broken down by type of diagnostic test, Jan 2006 to March 2014



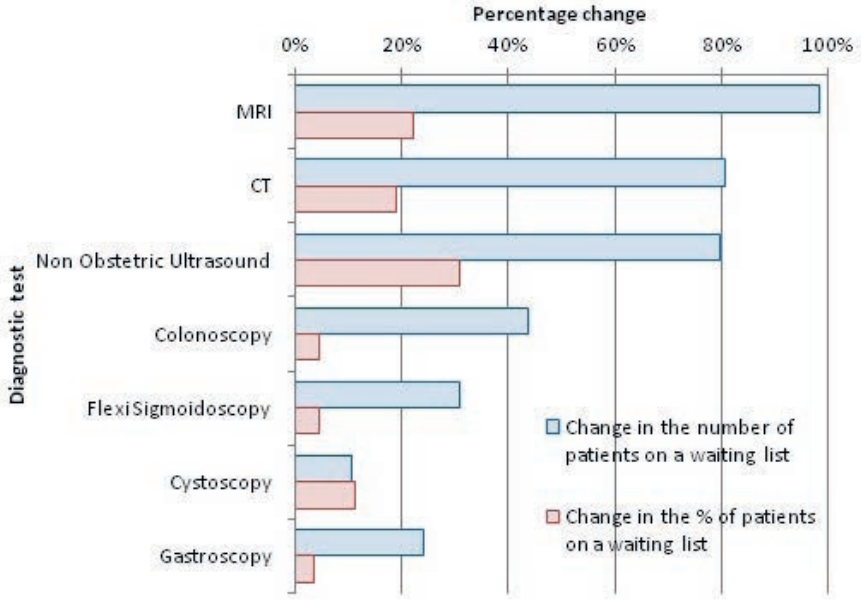
Source: NHS England, Monthly Diagnostic Waiting Times and Activity, 2006 to 2014

Figure 14: Number of patients on the waiting list at the end of month in England, broken down by type of diagnostic test, Jan 2006 to March 2014



Source: NHS England, Monthly Diagnostic Waiting Times and Activity, 2006 to 2014

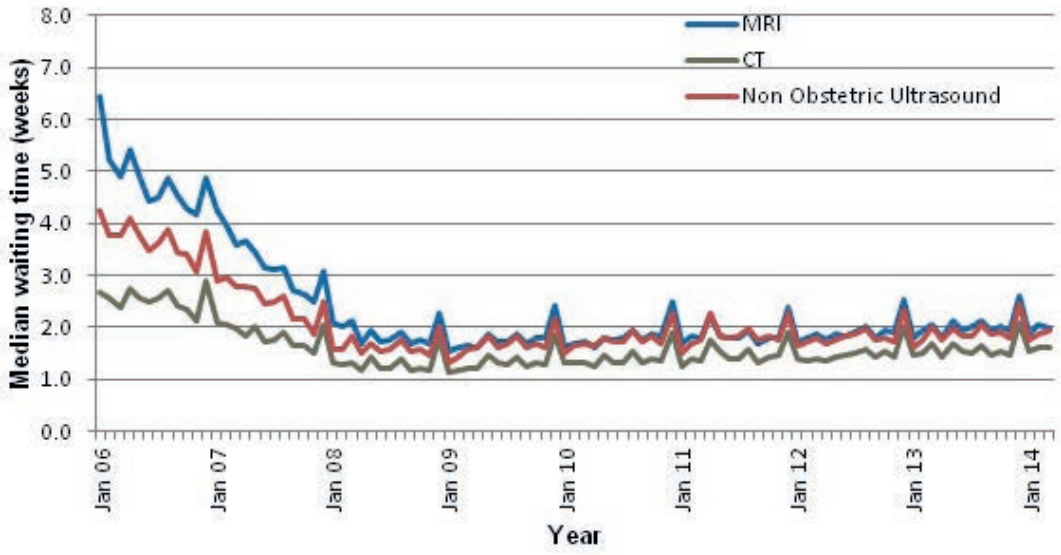
Figure 15: Percentage change in the number of patients on a waiting list and the % of patients on a waiting list in England, 2008-09 to 2013-14



Source: NHS England, Monthly Diagnostic Waiting Times and Activity, 2006 to 2014

A more important issue perhaps than the numbers of patients on the waiting list pertains to the length of time people are waiting to receive diagnostic tests. The median waiting time in England substantially decreased between 2006 and 2009 for all diagnostic tests, but particularly for the four endoscopy diagnostic tests (especially colonoscopy). Since 2009, the median waiting time for all tests has increased, although only by a relatively small amount compared to the substantial decrease in waiting times prior to 2009, and is currently around two weeks (Figures 16 and 17). There are peaks in the median waiting time for all diagnostic tests in the winter, and particularly in the month of December. This is because the measures of waiting time are subject to seasonality. The presence of the Christmas period and of the related bank holidays will have a negative effect on the median waiting times in December, as will any adverse weather conditions which would adversely affect the health service.[4]

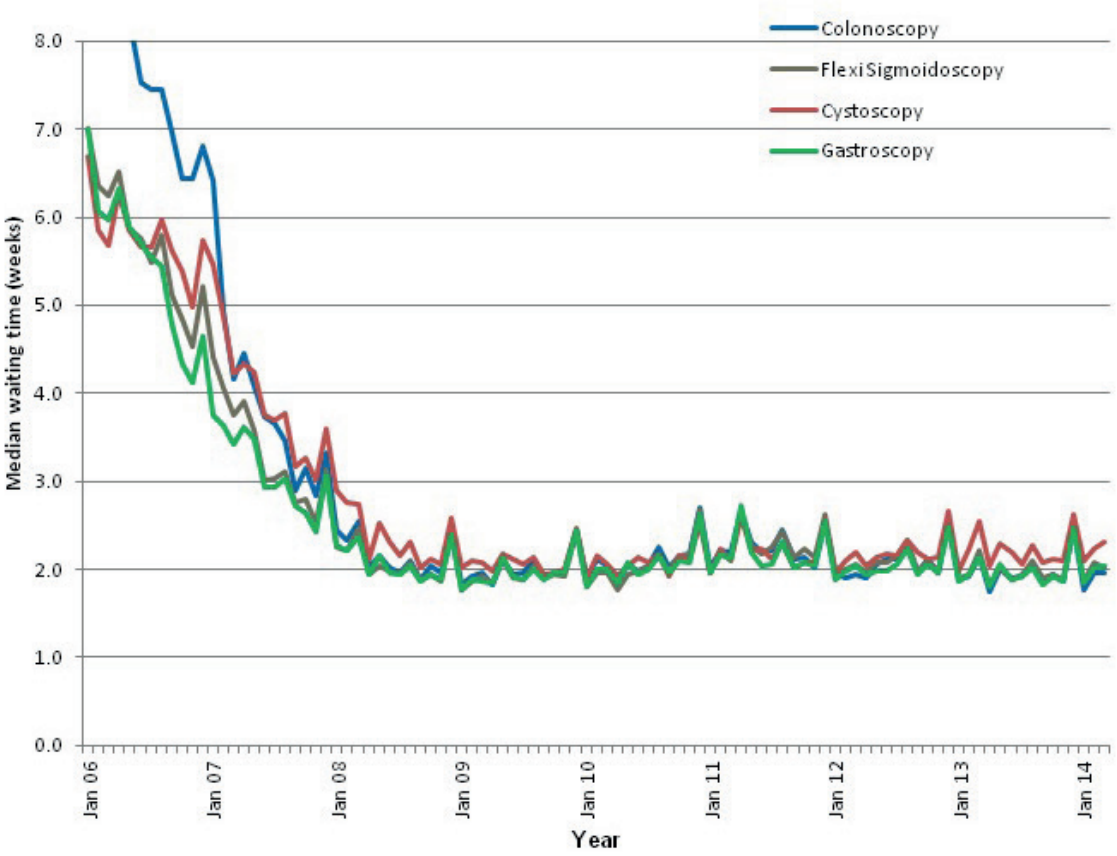
Figure 16: Median waiting time (in weeks) for a diagnostic test in England, broken down by type of test, January 2006 to March 2014.



Source: NHS England, Monthly Diagnostic Waiting Times and Activity, 2006 to 2014

[4] For more information see https://www.gov.uk/government/news/statistical-press-notice-nhs-diagnostics-waiting-times-and-activity-data-february-2013

Figure 17: Median waiting time (in weeks) for a diagnostic test in England, broken down by type of test, January 2006 to March 2014.



Source: NHS England, Monthly Diagnostic Waiting Times and Activity, 2006 to 2014

There was a large drop in the percentage of patients in England waiting six weeks or more for a diagnostic test between 2006 and 2009, and by 2009 the percentage was under 1% for the imaging tests and between 1% and 2.5% for endoscopic tests. There was a slight rise in the percentage of patients waiting six weeks or more in 2011 for all tests, but particularly endoscopic tests (peaking at 7.1% of all patients waiting for more than six weeks). Since 2011 the percentage has been falling for all tests, with data for March 2014 showing that:

- 1.2% of patients had been waiting six weeks or more for an MRI;
- 0.7% of patients had been waiting six weeks or more for a CT;
- 1.6% of patients had been waiting six weeks or more for non-obstetric ultrasound;
- 2.9% of patients had been waiting six weeks or more for an endoscopic test – the highest percentage being 5.8% for cystoscopy.

The percentage of patients waiting for 13 weeks or more for a diagnostic test in England has followed the same pattern, as would be expected. There was a steep decline in the percentage of patients waiting for all diagnostic tests between 2006 and 2009, and in 2009 the percentage of patients waiting 13 weeks or more for a diagnostic test was close to 0% for all diagnostic tests. Again, there was a slight increase in 2011, with a peak of 1.1% of patients waiting 13 weeks or more for endoscopic tests. Since 2011, the percentage has been falling for all tests, with data for March 2014 showing that:

- 0.1% of patients had been waiting 13 weeks or more for an MRI;
- 0.0% of patients had been waiting 13 weeks or more for a CT;
- 0.0% of patients had been waiting 13 weeks or more for non-obstetric ultrasound;
- 0.5% of patients had been waiting 13 weeks or more for an endoscopic diagnostic test – the highest percentage being 1.4% for cystoscopy.

DISCUSSION

The financial squeeze is being felt within cancer services, as it is in all areas of the NHS and public services more generally. It is remarkable, given the significantly increased activity over the last few years without a commensurate budget increase, that the NHS has continued to provide a service to cancer patients that is still largely meeting the standards set in terms of waiting times. In addition, patient experience is also reported as improving - with 88% of patients reporting their care was either excellent or very good in the last National Cancer Patient Experience survey published on 30th August 2013, (NHS England, 2013).

However, it seems clear that demand is starting to outstrip the resources available, as can be seen perhaps from the drop in performance against the 62-day waiting time target. It is unlikely that more efficiency gains can be achieved without them having a detrimental impact on staff, services and hence, patients. Staff are under increasing pressure to meet patient demand, and this is likely to have a longer-term effect on morale, motivation and well-being. There is also a lack of physical capacity, such as clinical space, in the system to accommodate more activity, and specific concerns regarding diagnostic capacity.

All of the information we have suggests that the number of people requiring care will increase in the future and demand for diagnostics is only likely to increase as early diagnosis improves. Though advancements in science and technology may mean that the profile of this increased activity changes, it is reasonable to suppose that without additional capacity waiting lists for diagnostic tests will increase. This in turn would have a knock on effect on the ability of organisations to meet 62-day waiting time targets. Given that we are already witnessing increasing variation between providers in meeting these targets, it is also reasonable to suggest that those better resourced providers may be in a better position to manage their waiting lists than those providers that are already struggling financially.

It is recognised that given the financial situation, further investment in cancer services cannot be assumed or taken for granted but managing with the same resource is likely to set services back and undo at least some of the good work that has been achieved to date.

RECOMMENDATIONS

1. **The Government should increase investment in cancer services, to ensure the NHS can meet rising demand and ensure our cancer outcomes become the best in the world. Investment is particularly crucial in diagnostic services, where risi ng demand is starting to outstrip the resources available.**

SYSTEM LEADERSHIP AND COMMISSIONING

While the national architecture has changed for the NHS in England as a whole, the reforms have also resulted in some key changes for cancer at both a national and a local level. These changes have significant implications for the way the system works together and the lines of accountability and responsibility for both the provision of, and commissioning of cancer services.

At a national level, the full time post of the National Clinical Director has been replaced by a part-time post; the National Cancer Action Team has been disbanded with elements of the work transferring to a new organisation NHS Improving Quality (NHS IQ); while the NHS Cancer Intelligence Network has been absorbed into Public Health England. Five national Programmes of Care (PoC) have been established which group together the specialised services NHS England is responsible for commissioning. One of these PoCs is Cancer and Blood which covers infection, immunity and haematology, as well as cancer. There are 17 Clinical Reference Groups (CRGs) within the Cancer and Blood PoC, 11 of which relate to cancer[5]. All CRGs related to cancer, including some that are not in the Cancer and Blood PoC like those for Specialised Imaging and Paediatric Cancer Services, are brought together in a Specialised Cancer CRG.

At a local level, the 28 Cancer Networks have been abolished, to be replaced with 12 geographically determined Strategic Clinical Networks (SCNs) and 12 Clinical Senates (CSs).

Cancer networks were originally 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. In broad terms Cancer Networks provided specialist commissioning expertise and advice on cancer services, leadership to ensure coordination of services across primary, secondary and tertiary care, and monitoring to ensure compliance with National Institute of Health and Clinical Excellence (NICE) Improving Outcomes Guidance.

The SCNs similarly, ''...support whole system and combined improvement endeavours with a particular focus on helping commissioners to reduce unwarranted variation in service delivery and support innovation,'' (NHS England, 2012) while CSs are ''...non-statutory advisory bodies of specialists intended to input into strategic clinical decision making and support local commissioning,'' (NHS England, 2012).

The SCNs have a wider remit than Cancer Networks, covering cancer; cardiovascular disease; maternity and children's; and mental health, dementia and neurological disorders. Each condition area has its own network arrangements under the umbrella of the SCN. The number and size of each condition area network has been left to local determination based on patient flows and clinical relationships. In some instances therefore there could be more than one condition specific network within the geographical area covered by a SCN. Each SCN is supported by a single team that also provides support to the condition area networks and the Clinical Senate.

SCNs are funded by NHS England - the total budget in 2013/14 was £42m (NHS England, 2012). This compares to the £33m budget that was previously allocated to the 28 cancer networks and 28 cardiac and stroke networks. Additional funding can potentially be secured from the commissioner and provider organisations operating within the geographical area covered by a SCN. However, the extent of this was not determined by this study.

NATIONAL LEADERSHIP

There was a strong view expressed by interviewees that the changes brought about by the reforms have led to a vacuum at a national level in England, in terms of the leadership and support needed to drive improvements in cancer services. People feared that cancer was already dropping down the agenda politically. Some specific elements lost as a result of the reforms such as the National Cancer Action Team, were seen as particularly problematic. Their loss was hampering not only people's day-to-day job but also their ability to create some 'headspace' to think through the

[5] Radiotherapy, PET-CT, Specialised Cancer, Thoracic Surgery, Upper GI Surgery, Sarcoma, Central Nervous System Tumours, Specialised Urology, Chemotherapy, Complex Head and Neck and Teenage and Young People Cancer

inevitable reforms to cancer services that would be required as a result of the ageing population, scientific innovation and financial constraints. It was noted that there was no overarching national group to advise on cancer strategy and that in addition, the ability to pull together the different parts of the system – primary care, acute care, tertiary care and social care had been weakened. The leadership role of NHS England was not well understood or indeed even recognised, and NHS Improving Quality was not seen as a particularly effective organisation.

> "What really seems to have to been the big change is the loss of central coordination and leadership, and I think what it felt like a year ago was that we were just tossed out into the sea.... There's no kind of overarching group to advise on strategy or standards or workforce...It risks fragmentation in terms of strategic development... I think there's the potential for inefficiency, in terms of service running and service delivery and I think there's a potential for that to lead to poorer outcomes."- National interviewee

On a positive note, the national Clinical Reference Groups (CRGs) were seen as being potentially useful in fostering better clinical engagement though it was noted that there is a lack of resources to support them.

> ''I think what could be quite a good system (clinical reference groups) is being hampered because there isn't even the most basic support to oil the wheels that might make things move along a little bit faster, and achieve efficiencies."
> - National interviewee

The CRGs don't cover all the common cancers however and this point was seen as particularly problematic, as new groups set up to cover these cancers were being entirely funded by charities. There were real concerns raised about this development, both because CRGs should be part of the "core business" of the NHS, and because of concerns that charities would bring their own biases and agendas to what should be an impartial process.

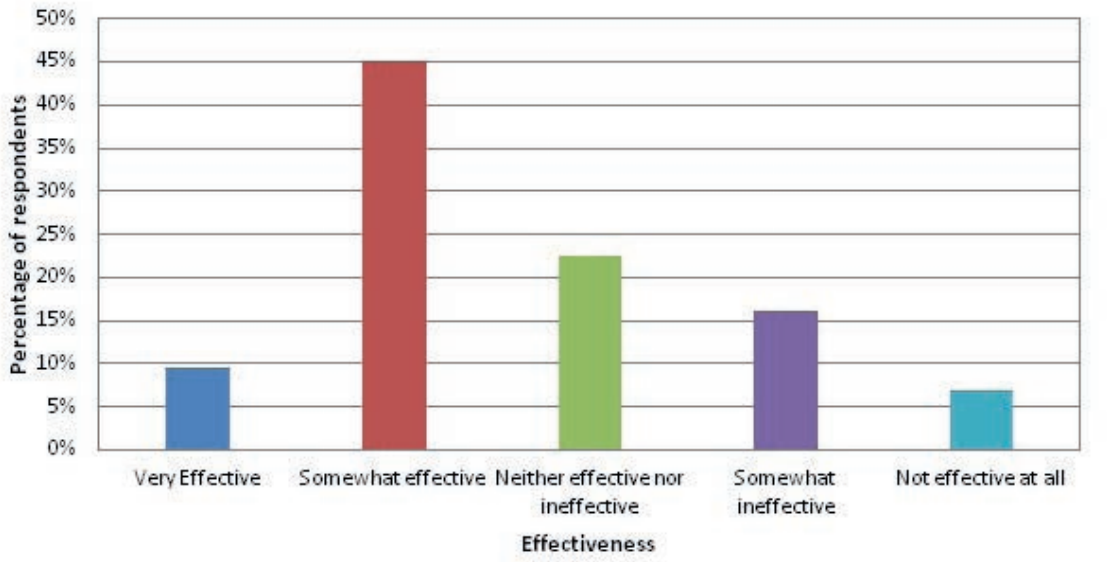
> "I think the Clinical Reference Groups on the whole are good. They've got a lot of good people on them. ...the national cancer director is beginning to try and establish a breast and lung clinical reference group. But they are actually being funded by charities ... which is outrageous, completely and utterly unacceptable. Not only because this is core NHS business, but because it then produces the bias. A charity has always got its own perspective."
> – National interviewee

The latest cancer strategy for England - Improving Outcomes: A Strategy for Cancer was published in January 2011. Though this is still a 'live' document, it is worth noting that while not prompted to do so, none of the interviewees or survey respondents made any specific reference to the strategy, or its objectives independently.

LOCAL LEADERSHIP AND STRATEGIC DEVELOPMENTS

Overall, there were mixed views on the effectiveness of local leadership for cancer services from survey respondents. Just over half of respondents (around 55%) considered local leadership for managing service performance and outcomes to be somewhat or very effective (Figure 18).

Figure 18: How effective is local leadership for managing service performance and outcomes:



Source: University of Birmingham Health Services Management Centre and ICF International survey data

The reconfiguration of Cancer Networks into Strategic Clinical Networks was repeatedly cited as an issue by survey respondents and interviewees. The pervasive view was that the disbanding of dedicated Cancer Networks had had a detrimental impact on the provision and quality of care received by cancer patients. This was a view expressed by commissioners and providers, and clinical and non-clinical staff alike.

"The impact of the removal of cancer networks cannot be overstated. They were the glue in the system that helped ensure co-ordinated pathways were delivered, patients had a voice in improving cancer pathways and commissioners had access to expert clinical groups with local knowledge. Whilst some of the work has been taken forward in SCNs, the funding and staffing is significantly reduced and NHS England has not provided a national framework from within which to plan SCN work and co-ordinate priorities...What we're left with is an inefficient and inadequate situation that leaves individual providers and commissioning organisations working in isolation trying to understand and address very complex issues."
- Commissioning support unit employee

"Just bring back the cancer networks please!" - Allied Health Professional

"The loss of the cancer networks is disastrous." Doctor, cancer specialist

There were views that the new Strategic Clinical Networks could provide better opportunities for whole system working, and a broader view of disease than the previously more geographically and condition constrained networks. This might, for example, allow a more strategic overview of service provision, or allow for more focus on early diagnosis - an issue of common interest across disease groups, and one which would impact upon greater numbers of people.

''I think the changes that were brought in from 1st April give us the opportunity to be able to do that [work collaboratively] ... because we [the SCN] will be able to see that across both geographical boundaries, CCG boundaries, provider boundaries and we will be able to hopefully advise them accordingly on what those services could and should look like.''
- Strategic Clinical Network Manager

"So in the old regime there tended to be... more of a focus on where one sited the tertiary surgical services for cancer, which actually is only going to make a difference for very small numbers of patients. Whereas now quite a lot of the strategic clinical networks have got a bigger focus on the early diagnosis end, which is very positive because in terms of saving lives then that's probably where they should be putting their attention."
– National interviewee

REBUILDING RELATIONSHIPS AND UNDERSTANDING NEW ROLES AND RESPONSIBILITIES

Though the loss of the Cancer Networks was felt by many, the impact was experienced differently in different parts of the country. It appears that where the loss was felt least, this was the serendipitous result of staff who previously worked for the Cancer Network remaining in the new SCN and essentially recreating what they had previously, though on a less well-resourced scale.

> ''I think it's because I know some of the people that have gone into the strategic clinical network so, you know, we have established relationships and I think that's really fortunate.''
> - LTC Commissioning Lead, CCG

Regardless of how many people previously working on cancer have remained in the same community, interviewees were united in the view that a great deal of time and energy has gone on rebuilding the relationships that existed previously.

> ''Well, I mean the word I would use is fragmentation and that sounds very negative I know. But what me and my colleagues have spent a lot of time doing is rebuilding the kind of partnerships and links that we had before the changes took place... and so we've had to spend a lot of time just gluing the bits back together really to make it work.''
> – Public Health specialist

The variation in who does what and in which organisations people are based has led to some particular difficulties for people over and above re-establishing relationships. Confusion over who the decision makers are and who or which organisation is responsible for which parts of the system is leading to worries over both duplication of effort and gaps in attention, so that important aspects of delivery may get over-looked, or are minimised.

> ''...we're all brand new at doing this and none of us are quite sure what the other one's doing so, you know, the CSU are not quite sure what the CCG's thinking and, as a CCG, I'm not quite sure what the network's thinking and the network's got no idea what the two of us are doing! And I think the danger is ...we could be reinventing the wheel when we don't need to and is there other stuff that should be happening and isn't....''
> – CCG Commissioning Lead

Examples provided of areas that might receive less attention now included the peer review process, provider performance management, through the use of routine activity and outcomes data, and effective communication with GPs.

> ''...I think that one of the things that we have lost perhaps is more of the routine data that we used to get sent as a PCT that we don't get quite so much as a CCG. ...the one thing our CSU does not strictly speaking have is a performance team. We do have one member up there that does performance .... So if there's anything going on out in the services themselves, it will take a while probably to come to us ...to be resolved.''
> – CCG Commissioning Lead

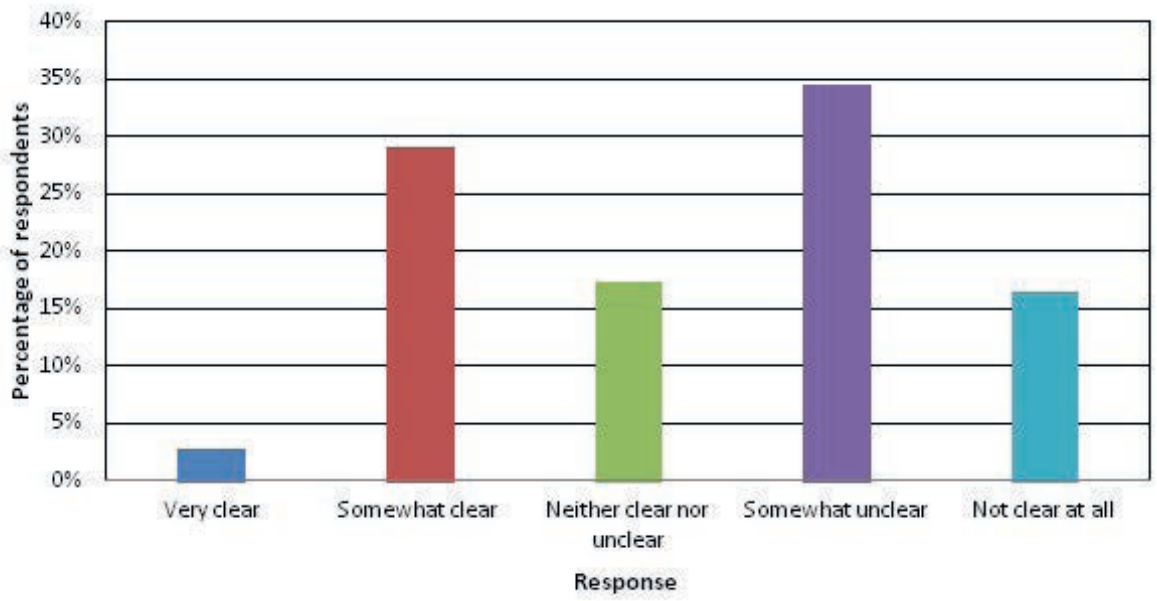
> ''...my clinical lead has basically asked me to send information out to the GPs. That's coming presumably from the cancer networks who presumably now have lost all their links, I don't know how they used to do it before, but they obviously don't have a budget for a comms team and they probably don't have the links to send them out direct to GPs anymore, so they ... asked us if we would do it .... Without that, I don't know who would be doing it.''
> - CCG Commissioning Lead

A CSU interviewee also explained that they do not receive identifiable patient data in the same way as PCTs used to do. This means that if they wanted to send a questionnaire or another kind of communication out to patients, they were relying on the goodwill of their providers to help them do so. There were other examples of these kinds of 'work arounds' in the system, enabling people to get the job done but not necessarily as efficiently or as effectively as might have been the case with the previous infrastructure.

The survey specifically asked respondents the extent to which they felt there was clarity about the new architecture for planning and commissioning cancer services, as well as their understanding of the roles and responsibilities of various key bodies within that architecture. It is

clear that this is not well understood with 51% of respondents reporting that these are 'not clear at all' or 'somewhat unclear', compared with 29% who considered them to be 'somewhat clear' and 3% to be 'very clear' (Figure 19).

Figure 19: From your perspective, how clear are the roles, responsibilities and accountabilities for planning and commissioning cancer services?

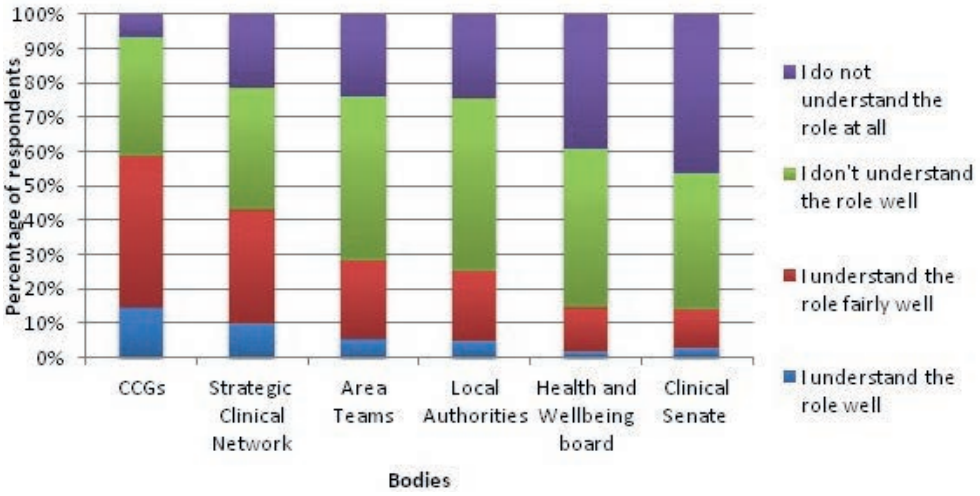


Source: University of Birmingham Health Services Management Centre and ICF International survey data

Of the specific bodies with responsibilities for planning and commissioning services along the cancer pathway, CCGs were the best understood by survey respondents, with 59% stating that they understand the role of CCGs 'well' or 'fairly well'. Fewer respondents felt they understood what role other bodies had in planning and commissioning cancer services to the same extent (Figure 20):

- **Strategic clinical networks:** 43% of all survey respondents understood their role well or fairly well, 36% didn't understand the role well, and 21% didn't understand it at all
- **Area teams:** 28% understood their role well or fairly well, 48% didn't understand the role well, and 24% didn't understand it at all
- **Local authorities:** 25% understood their role well or fairly well, 50% didn't understand the role well, and 25% didn't understand it at all
- **Health and wellbeing boards:** 15% understood their role well or fairly well, 46% didn't understand the role well, and 39% didn't understand it at all
- **Clinical senates:** 14% understood their role well or fairly well, 40% didn't understand the role well, and 46% didn't understand it at all.

Figure 20: Do you know what role each of the following bodies has in the planning and commissioning of cancer services in your area?



Source: University of Birmingham Health Services Management Centre and ICF International survey data

Comments from interviewees reflect the same low level of comprehension of the role of new organisations.

> ''To be totally honest with you, I don't know what a clinical senate actually is and it may be that actually that's what our networks have morphed into but I'm just calling them by the old name!''
> – CCG Commissioning Lead

> "I don't quite understand what they're for (Strategic Clinical Networks), but I suppose they're supposed to set some of the functions of the old network groups, but quite how you do it when you cover just an enormous spread of disease areas and specialities I don't know."
> – National interviewee

Few interviewees had any knowledge of the role Health and Wellbeing Boards might theoretically have in the oversight of the commissioning of cancer services, and no interviewees commented on this role having any traction in practice in their local area.

> ''Again I think the Health and Wellbeing Board is still finding its feet because it's a relatively new and relatively sort of untested part of the system. ... members of the Public Health Team regularly present on issues to the Health and Wellbeing Board .... They obviously are responsible for endorsing the Council's ... Health and Wellbeing Strategy ... in which cancer and prevention of premature mortality is there. But I would say in terms of managing any detail their knowledge is quite sketchy. And they don't appear to be all that interested .... because there's so many competing issues.
> – Public Health specialist

> ''Health and Wellbeing Boards ... I don't think they're in any way contributing to the system. I think the dialogue is still between commissioners and providers.''
> – National interviewee

The new patient body HealthWatch was not seen to be engaged with the cancer agenda in any obvious way either. Interviewees suggested that though there is a legitimate role for them in monitoring and scrutinising the delivery of cancer services, their remit is too broad to be undertaken in any meaningful way that is likely to have a positive impact for cancer services or cancer patients.

> ''The trouble is HealthWatch is covering all of illnesses and aspects of everything to do with health now ... I don't know if HealthWatch is the right animal to point up individual areas, particular problems– so we're going to have to rely on our surgeons I suppose to do the fighting for us now.''
> (Patient)

DECISION-MAKING

Transparency in decision-making was also an issue for interviewees, the fear being that work on new models of care might not always be taking place within the sight of commissioning decision

makers, potentially also wasting time, effort and money.

> ''I got a random phone call last week from a gentleman who's just started working for them (the Strategic Clinical Network) around survivorship ... he was basically saying 'well what do you know about your survivorship in terms of contracts and things' ...and they've got these big ideas about how they would like survivorship to be built into contracts, ... and it sounds horribly like if you hadn't managed to find us, they'd be going off doing all this work and then will come to us with a fait accompli to say 'well that's what you now need to do' and without him understanding that actually we don't have the money to do that or yes that's a wonderful idea,''
> – CCG Commissioning Lead

Decision making for larger scale investment also appears opaque at times, with genuine confusion over who is accountable for decisions that involve more than one organisation. This was seen as unhelpful and hindering a shared sense of responsibility for regional system management.

> "I used to know exactly where to go, exactly who to contact either nationally or regionally about an issue. ... And I haven't got a clue now...We've just had a regional issue where [x service] has been allotted to [another provider], without any, as I can see, consultation with any of the oncology teams or the health authorities locally. And I've spent the last week trying to find out who's responsible. I still don't know ...it's very difficult to know how to find out, how to make contact, how to influence, how to press buttons which make things happen. It's a mess."
> – National interviewee

There were also reports of uncertainty over responsibility for decision making leading to delays.

> ''We did do all the paperwork, all the documents, ready for procurement and then we hit the change responsibilities whereby NHS England now procures and has the contracts for radiotherapy. And whilst our area team have been very supportive in principle of an expansion, I think they don't have the governance arrangement in place yet to be able to make a decision locally. Or it's not clear where the governance lies for fairly major investments like that.''
> – Associate Director, Clinical Networks and Senates

FRAGMENTATION OF COMMISSIONING

Local Authorities are responsible for commissioning or providing a range of preventative services such as smoking cessation, or weight management programmes. NHS England is currently responsible for commissioning radiotherapy and chemotherapy services and some specialist treatment for either rarer cancers or high cost treatments, as well as primary care services, from where most patients still receive their initial referral. CCGs are currently responsible for commissioning certain elements of treatment for more common cancers while the final piece of the jigsaw is the screening programmes now commissioned jointly by Public Health England and NHS England.

Perhaps not surprisingly, a particular aspect of the new architecture which was causing many interviewees concern was this fragmentation in the commissioning of services along the patient pathway.

> ''...this fragmentation of commissioning hasn't made it easy for a pathway like cancer ...even a very common one like breast cancer - you've got something at the beginning around primary care and how they respond to patients in their care, who may or may not have breast cancer. You've got something in secondary care about patients being referred in and specialist commissioning because a lot of breast cancer patients would have radiotherapy and chemotherapy, but also the screening programmes going on in breast cancer, which is NHS England. So you know even on a standard breast cancer pathway, you're going to get a number of commissioners and making that in to a really good, quality service so the commissioners are working in the same direction and not confusing the hell out of everybody, is more of a challenge ...''
> – CSU Cancer Commissioning Manager

> ''It might be the worst thing that the NHS has done, the separation at source of the

responsibilities for commissioning, so the money flows right from the top in different directions, that creates significant room for arguing about whose responsibility is for what services, and secondly creates incentives for people to support their area at the expense of another commissioner.'' – Network Manager

"The multi fragmented way of commissioning and delivering care is MUCH worse than it was - roles of SCN , CCG, LAT, Monitor, CQC, senates etc are all intermingled and no one can make a decision etc. It all needs rationalising into one place".
– Doctor, cancer specialist

According to the findings, the complexity of local and specialist commissioning arrangements appear to be hampering efforts to take a 'whole pathway' approach to service redesign.

"Specialist commissioning needs a complete re-think. Cancer care pathways frequently cross the boundaries between the primary care and CCG commissioning remit and areas that are notionally the responsibility of 'specialist commissioning'. Effective pathway development is currently undermined or blocked by inertia, ineffectiveness, lack of communication and lack of insight demonstrated by specialist commissioners (which is partly the consequence of ineffective/under-developed Area Teams)."
– GP with CCG role

"The specialist commissioning teams cannot take this work on, and local CCGs are ignorant of their need to be involved in cancer commissioning - in the belief this is all done by specialist commissioners."
– Doctor, cancer specialist

There was no expectation that everything should be commissioned at either a national or a local level. And though fragmentation was a genuine concern, specialised commissioning arrangements were also seen as being helpful when it came to better standardisation of practice and ensuring more consistent access to treatments such as radiotherapy. What is needed is better co-ordination and clear lines of accountability in order to prevent gaps in provision or at least inefficiencies, and a pathway which is uncoordinated and confusing for the individual patient.

"Essentially, the creation of multiple organisations, the increased autonomy of healthcare providers, and the splitting of commissioning responsibilities makes life very difficult when the focus is on a cancer patient pathway that runs across multiple organisations and is commissioned in piecemeal fashion by different commissioners. ... cancer services in some areas are left with ... no-one in the middle facilitating the piecing together of the bits in the most efficient manner."
– Strategic Clinical Network (Cancer) Quality Improvement Lead

''Commissioning is defined in terms of who pays for the operation, who pays for the outpatient appointment, at no point does it say, whose responsibility it is to fund enough nurse specialist input?'
– Network Manager

''All disconnects in pathways are a potential ditch that patients fall into... And anywhere where somebody can say 'well that's not my job, it's his' are potential areas for things to go wrong.''
– GP and Clinical lead for LTCs, CCG

COMMISSIONING EXPERTISE IN CANCER SERVICES

As a result of the widespread movement of staff from the old organisations into different parts of the new architecture, it is down to chance to some extent if cancer expertise has been maintained in local areas or whether it has had to be re-created. It appears that in some areas this is affecting the abilities of CCGs to be effective commissioners of cancer care.

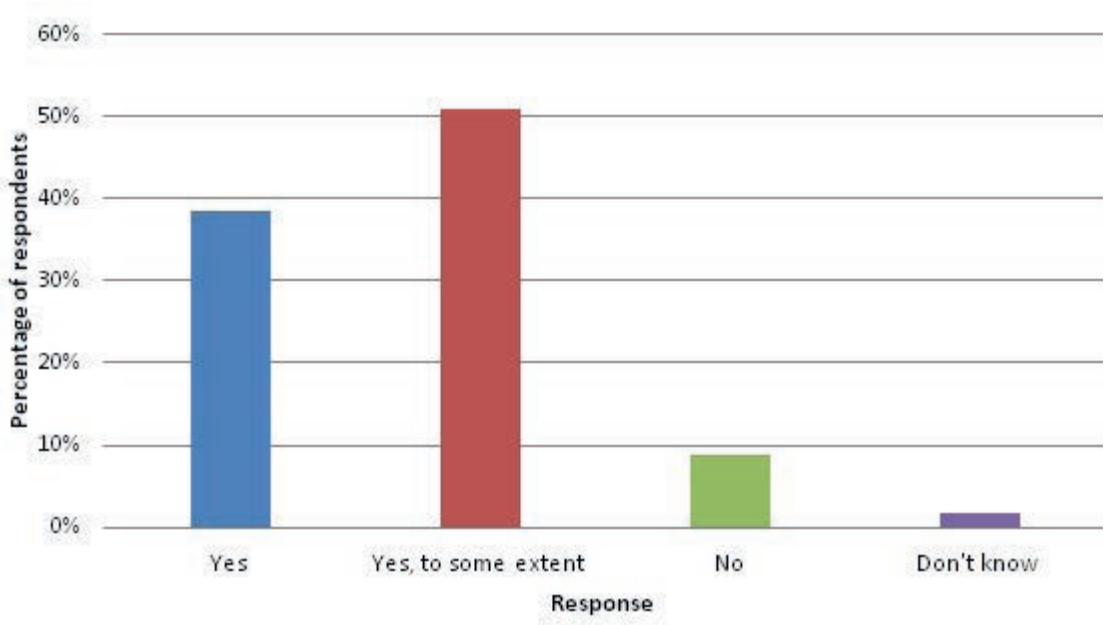
"...broadly speaking the people that used to commission cancer are no longer commissioning cancer, and the people who are commissioning now used to be doing something else. And the impact is that ... it's contracting. It's saying, 'Whatever we had last year we'll have 3% more for the same money, please.'"
– National interviewee

Despite reports of a deficit of expertise, survey respondents involved in commissioning (including

CCG/CSU staff, GPs with CCG roles, and those working in area teams) reported being able to access sufficient knowledge and expertise to commission cancer services effectively. Of the 57 respondents directly involved in commissioning, 89% agreed they could access clinical knowledge and expertise to some extent at least, and 77% agreed they could access analytical knowledge and expertise to some extent at least, (Figure 21).

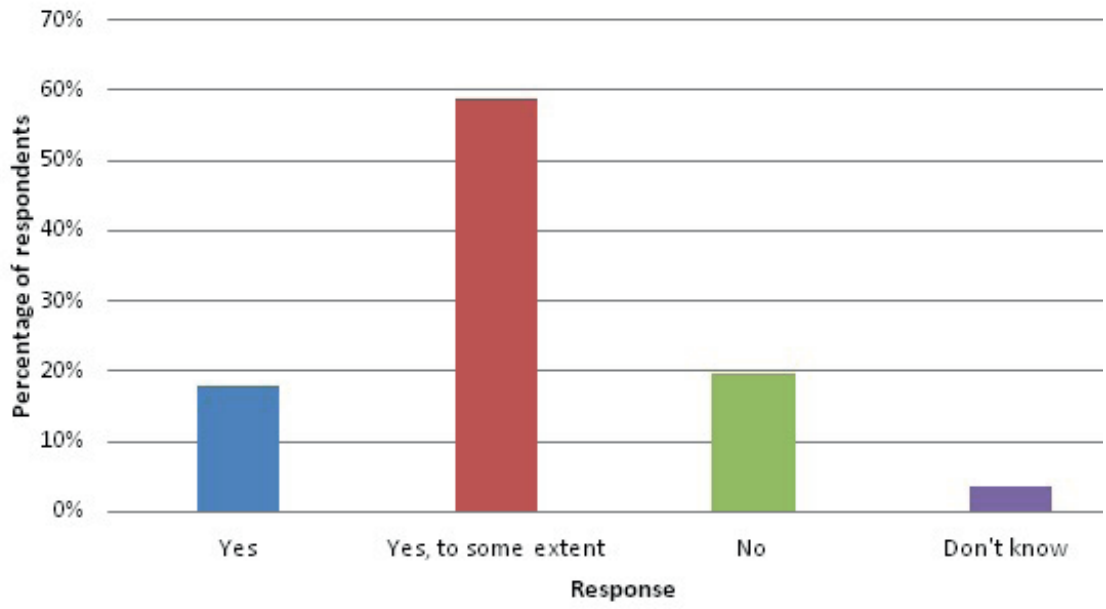
Figure 21: Are you able to access sufficient knowledge and expertise to commission cancer services effectively?

a) Clinical knowledge and expertise



Source: University of Birmingham Health Services Management Centre and ICF International survey data

b) Analytical knowledge and expertise



Source: University of Birmingham Health Services Management Centre and ICF International survey data

MAINTAINING MORALE

A good deal of dedication and commitment has been shown by staff in order to keep things working on the front line for patients, in spite of the challenges and frustrations elsewhere. This level of effort has to be sustained in the face of rising activity, cost pressures and the need to adapt to new developments in cancer treatment. Interviewees talked of a workforce that was at best weary of change, and at worst experiencing low morale and burn out.

> ''I think keeping the workforce motivated is a big challenge... I think it's harder to keep engagement, people will you know, come in, do the job, but they're not going to keep putting in the extra that they perhaps have done previously, they're tired and undervalued I think.''
> – Cancer Services Manager, Acute Trust

> "Everybody's feeling very disenfranchised, very unmotivated, very unloved by the whole system. It just doesn't, it hasn't got anything like the same degree of passion and engagement that it had."
> – National interviewee

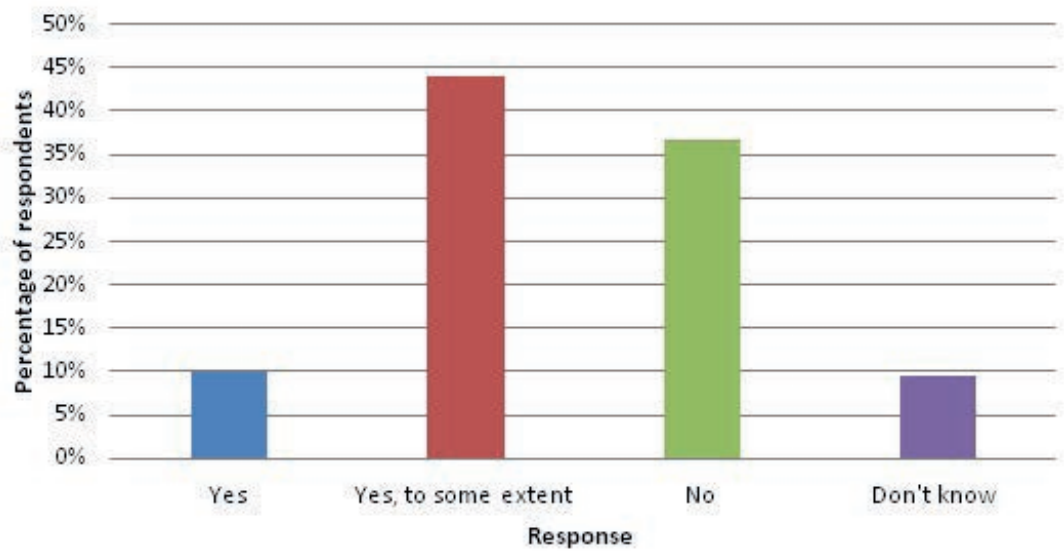
COMMISSIONING PUBLIC HEALTH SERVICES

As with other aspects of the new architecture, there is some confusion as to who is responsible for the commissioning of public health input into cancer pathways. The relationship between NHS England and Public Health England was perceived as being weak with little co-ordination or development of joint strategies. There was also a lack of clarity over the roles of Local Authorities and Public Health England in commissioning screening programmes and how to access this support.

> ''... obviously the screening sits with Public Health England and with our public health teams in the local authority and we've definitely lost links to our public health teams in the local authority. I have tried and asked repeatedly and I do not know who leads on cancer for the local authority and I don't think our cancer networks necessarily know very well either.''
> – CCG Commissioning Lead

The survey also asked respondents for their views about the priority given to prevention and early diagnosis in their area. Views were mixed; 54% of respondents agreed that enough priority was given to prevention and early diagnosis of cancer, although 37% disagreed (Figure 22).

Figure 22: Do you think enough priority is given to prevention and early diagnosis of cancer in your area:



Source: University of Birmingham Health Services Management Centre and ICF International survey data

The idea that more could be done to improve prevention and early diagnosis was echoed in survey comments; this was frequently cited as one of the most important advances that needs to be made to improve cancer services and outcomes:

> "So early diagnosis is essential. ...But the approach has been pathetic in that the medical politician elite believe it is due to poor doctoring. Actually most cancers below the surface of the body are silent. So early diagnosis requires tumour markers and screening."
> – Doctor, cancer specialist

Interviewees with a specific public health remit commented on the more political aspect of working within a Local Authority and the different kind of relationship that it was necessary to develop with elected councillors when it comes to commissioning services.

> ''What has changed... is working within the political context of local government so the decision making process is very different... in the old way we might want to produce a business plan, go to the executive team and talk about evidence from randomised controlled trials, various different reviews from medical journals, look at some quality of life indicators to describe an investment of x to produce y amount of savings, so very sort of scientific because you were talking to professionals... We're now talking to elected members so putting in front of them statistical tables is probably not the right thing to do... what we can say is investing in a new weight management service for adults and for children has real health benefits for those individuals. So it's telling the story in a slightly different way.''
> – Assistant Director of Public Health

It was reported that depending on a councillor's political ideology, or personal views, it might be more difficult to persuade them of the need to commission certain services. The added complexity and variation in practice of working in a system with single and two-tier authorities was also commented on.

> ''I have eight districts with eight environmental health teams with eight housing officers with eight leisure services so that makes it more complicated that bit of it.''
> – Assistant Director of Public Health

In spite of getting used to new ways of working in Local Authorities, Public Health interviewees reported more scope than they had previously enjoyed in the NHS for developing services.

> ''We've been given far greater freedom to spend... so that's allowed us to invest in programmes and services which historically we didn't. That's really, really positive... we're increasing our responsibilities and we're developing and commissioning services which are new to xxxx, which is fantastic.''
> – Assistant Director of Public Health

A more collaborative style of working across a range of departments within Local Authorities was also viewed very positively. A specific example of this came from one Public Health team which had persuaded its local Councillors of the link between fast food outlets and obesity, ''...and they're no longer just putting food outlets up willy nilly'' - Public Health Consultant

> " [the shift to local authorities has] certainly made life easier... we're having closer, more productive conversations.''
> – Assistant Director of Public Health

Another positive aspect of the move of Public Health into Local Authorities was the different attitude to commissioning which was perceived as being more robust and more tightly focused on what commissioners were getting for their money.

> ''...we're very much now in the world of procurement, tendering ...the advantage is that the market dictates how much you pay, so that's quite good.... [also it] forces you to have a really robust service specification ... that sometimes was lacking when you were NHS to NHS commissioning. I think there are lots of examples where, you know, the NHS...were paying money to a provider and there was no service specification ...we're now putting in really strong service specifications, really good outcome measures and KPIs and regular monitoring meetings and by and large most of the providers have really welcomed that because they said it's the first time somebody is interested in my service.''
> – Assistant Director of Public Health

It appears that the sharing of good practice runs both ways with reports of positive changes in the way that Local Authorities work and think about public health problems too.

''What I noticed when we came to the local authority was that they used to base quality and cost in opposite directions, so quality might be something like 40% and cost might be something like 60%, so we got them round to thinking that actually quality should be the main thing rather than the cost.'' - Public Health Consultant

DISCUSSION

The findings here are dominated by feelings of confusion about who does what within the new architecture and frustrations over a lack of support and resources to get things done. The fears that the national focus in England has been diluted were very real. Since the publication of the Calman-Hine Report in 1995, targeted policies and programmes and strong investment had seen significant improvements in the delivery of cancer services with increased capacity in workforce and facilities, development of national pathways, and the introduction of national standards, targets and screening programmes. However, the perception is that the mechanisms that had been put in place to drive improvements and provide expert advice and support since 1995 have subsequently been eroded as a result of the reforms.

There is a clear wish for cancer to have a higher profile nationally, with a more robust leadership infrastructure that can ensure better co-ordination across the many different elements of the system, in both the commissioning and provision of cancer services, and a clearer articulation of responsibilities and accountabilities for each constituent body. The distinction between what can and should be done at a local level, and what should be done nationally in order to maintain consistency of standards, also needs further consideration and subsequent articulation.

Adding further layers of bureaucracy and changing the system in a wholesale way is clearly not the answer for a change weary NHS. Instead, the current system has to work better for people. The roles of existing organisations need to be better defined and understood, and appropriately resourced to do the job that is expected of them. There are already refinements being made to the new architecture and some of these changes may well bring people the improvements they feel are needed.
It would appear that the national 'voice' for cancer patients has not been enhanced by the creation of HealthWatch, leaving it up to chance whether cancer features as a priority for the local organisations. Without strong patient representation, there is always a danger that services do not respond as well as they could to patient needs and that important strategic decisions are made in a vacuum. The presence of lay members on the national Clinical Reference Groups is undoubtedly helpful but could lead to a narrowing of interests.

There are signs of positive changes, however, with the potential for the national Clinical Reference Groups to make a strong, clinically focused contribution to the cancer agenda, and the benefits to be gained from closer working between Public Health teams and their Local Authority colleagues. There is still enormous passion, drive and commitment to improve services for cancer patients even if the impression is that this has become increasingly difficult. These positives must be built upon and supported appropriately.

RECOMMENDATIONS

2. The Department of Health should create a recognised cancer leadership team to provide support and strategic oversight to NHS England, Public Health England and the Department. Building on the work of the National Clinical Director for Cancer in NHS England, a similar lead role should be created at Public Health England, with a cancer lead at the Department of Health given clear responsibility for strategic oversight.
3. The Department of Health should review Improving Outcomes: a Strategy for Cancer in light of the changes to the NHS structures and update it as appropriate to ensure it is fit for purpose for the new commissioning system. The Department should make a concerted effort to communicate the relevance of the Strategy to the new commissioning system.
4. NHS England should provide greater support and funding to the Clinical Reference Groups to enable them to achieve their potential for system development and ensure they drive real improvements.
5. The Department of Health, NHS England and Public Health England must urgently clarify and communicate the responsibilities of the different commissioners of cancer services. Strategic Clinical Networks should map out commissioning responsibilities for their geographical area and ensure commissioning organisations are working together to provide coordinated cancer services.

SERVICE DEVELOPMENT AND IMPROVEMENT

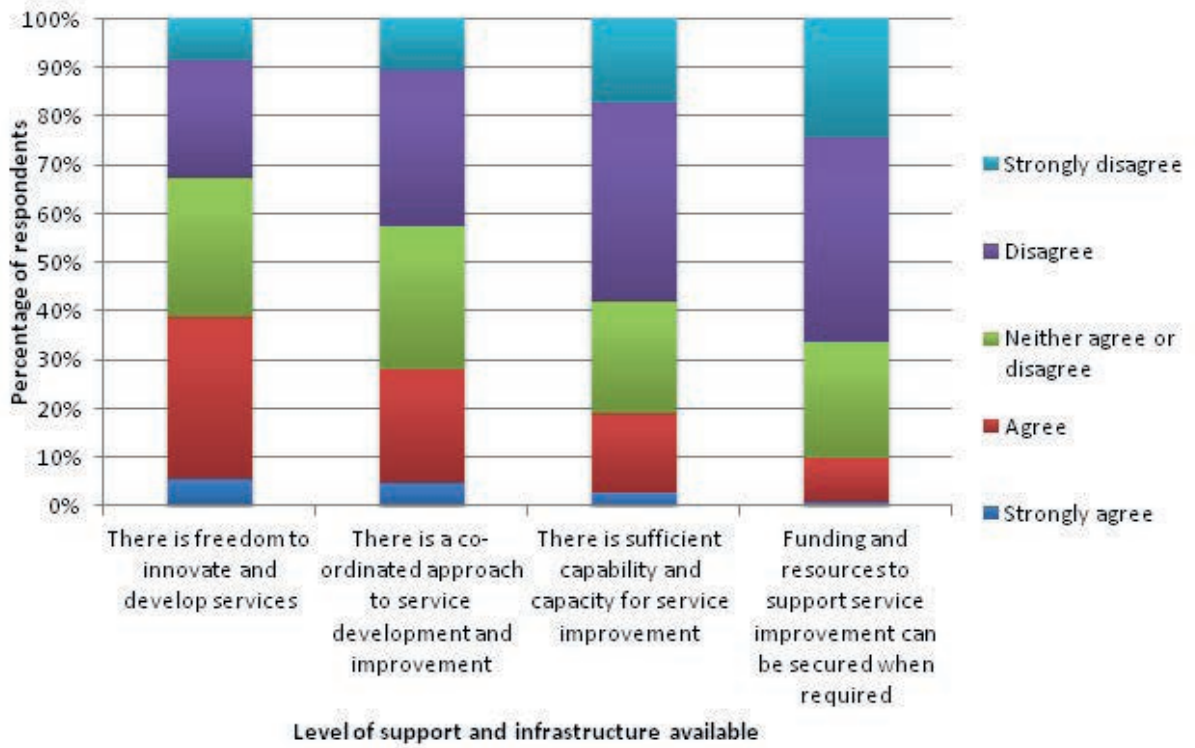
As noted in Cancer Research UK's 2012 report, disruption is caused before, during and after large-scale change and studies suggest that any positive effects of reorganisation may take some time to be achieved. Reports suggest an organisation's performance takes between 18 months and three years to return to pre-change levels. In this follow up study, interviewees reflected on this phenomenon, talking about a 'hiatus' in cancer service development in England over the course of the last couple of years and expressing regret that the work people can see needs to be done to improve services has not yet been tackled as a result of the combined fall-out of the reforms and efficiency savings.

It is by no means certain that the mere passage of time will redress this. The findings from both interviewees and survey respondents note the underlying issues that they feel need to be addressed in order to drive service improvements.

CREATING THE HEADSPACE

Survey questions explored the level of support and infrastructure in place to develop and improve cancer services at a local level. Respondents reported that freedom to innovate was less of an issue than the practical enablers. Just over a third of respondents (33%) felt freedom to innovate was a concern, compared to two-thirds of respondents who felt that funding and resources were an issue and 58% of respondents who felt that capability and capacity were concerns. Forty-three percent of respondents felt that there was a co-ordinated approach to service development and improvement in their area (Figure 23).

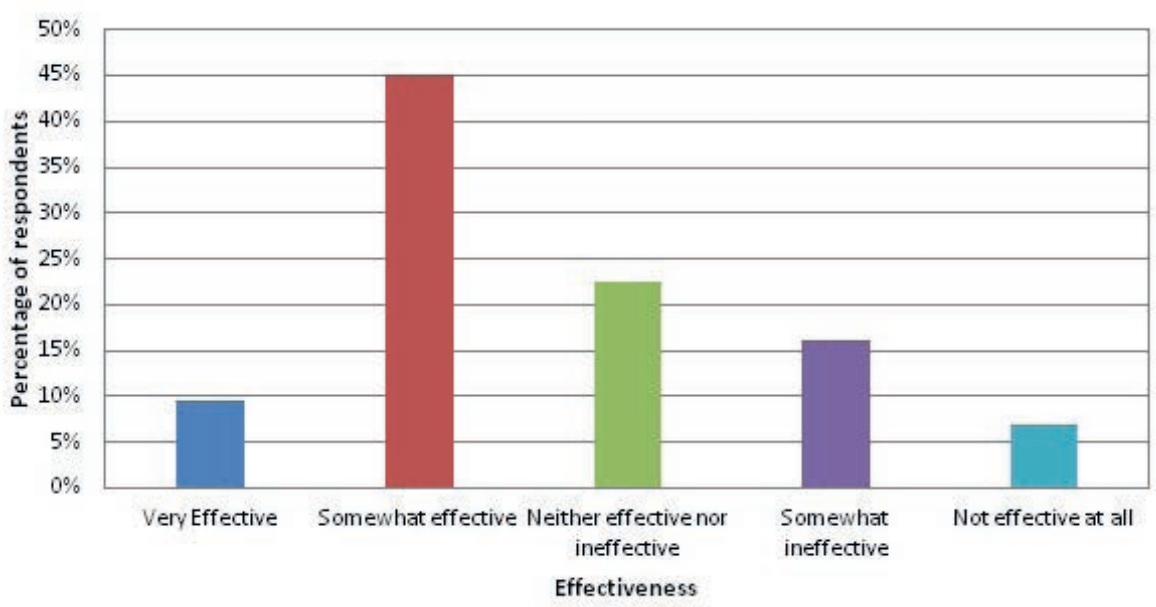
Figure 23: Thinking about the development and improvement of cancer services in your area, would you say:



Source: University of Birmingham Health Services Management Centre and ICF International survey data

Furthermore, 51% of respondents reported that local leadership was somewhat or very effective for driving service improvement and development (Figure 24).

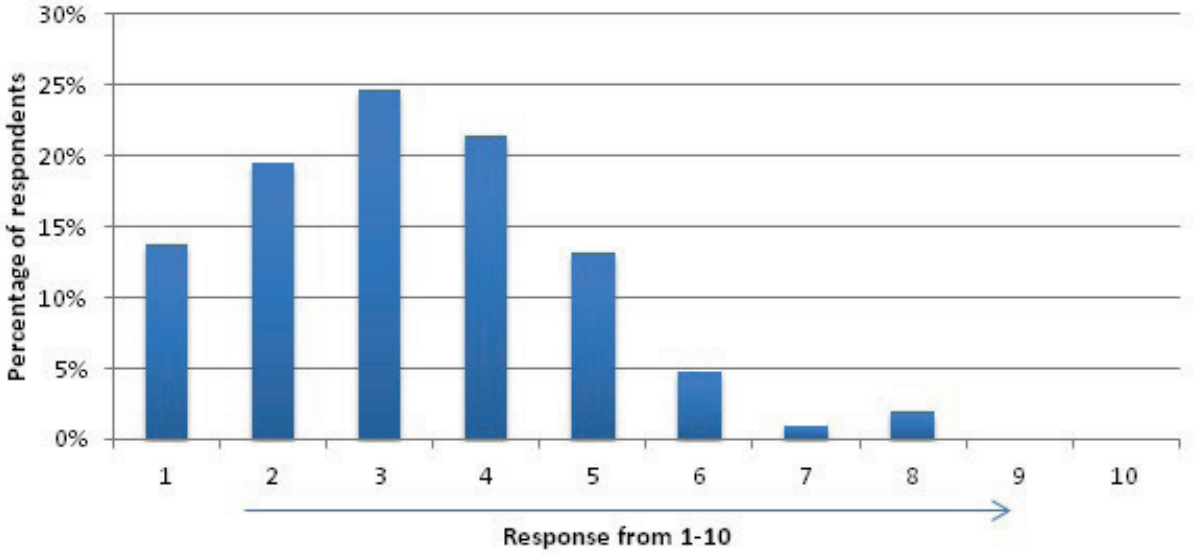
Figure 24: How effective is local leadership for driving service improvement and development:



Source: University of Birmingham Health Services Management Centre and ICF International survey data

Survey respondents were asked to specifically assess the impact of the financial environment on the development and improvement of cancer services, with a rating of 10 indicating a very positive impact and a rating of 1 a very negative impact - 79% of respondents gave a rating of 1-4, 13% a rating of 5, and 8% a rating of 6-8, again with no ratings of 9 or 10. The average rating for this question was 3.3 (Figure 25), suggesting a significant level of pessimism.

Figure 25: To what extent is the current financial environment affecting the development and improvement of cancer services?



Source: University of Birmingham Health Services Management Centre and ICF International survey data

These points were reflected in the qualitative findings, with comments addressing the themes of funding, capacity and coordination as barriers to service improvement, service development and innovation.

"The lack of funding for increasing capacity, tracking cancer pathways, supporting MDTs, performing audits and developing multi-disciplinary clinics is the main reason why services cannot really improve as much as all the cancer teams would like."
– Doctor, cancer specialist

"We need more funding. Instead of progressing/developing our cancer services which are already significantly underfunded, our services are actually being cut. It is becoming impossible to deliver all the new cancer targets and quality of care is deteriorating."
– Allied Health Professional

"Capital investment will be required to ensure cancer services in our area are sufficient in quality and capacity to manage the demand."
– Non-clinical manager

"The direction should be for more integration of acute and primary/community care. However, the multitude of organisations now involved and the lack of national funding for the continued support of networking and coordination across professionals and organisations in all these fields is hampering the ability to make these changes."
– Strategic Clinical Network Cancer Quality Improvement Lead

The reduction in support and resources for leading strategic developments in cancer services was raised many times with interviewees commenting specifically on the role that the Cancer Networks had previously taken in this regard.

''I guess there are less of us concentrating on cancer. When I first came to the cancer network in 2009, there were about between 25 and 30 support team posts looking purely at cancer. I've now got about 30 people in the team but they're looking after obviously another three strategic clinical networks and the senate. So the resource has inevitably been diluted and we can't roll our sleeves up on the sort of service improvement end of things as much as we would have previously been able to.''
– Associate Director, Strategic Clinical Networks and Senates

"... we lost some very good people in the cancer networks who were coming to the end of their careers or decided there was one too many reorganisations to start another one and left. So yeah absolutely it's taken us a bit of time in certain areas to get up to speed,''
– CSU Cancer Commissioning Team Manager

A broader remit, combined with a real-term cut in budget for cancer and staff resources inevitably means that the SCNs can no longer support some useful elements of the earlier Cancer Network architecture. Of particular note was the end of tumour site-specific groups in many areas, partly through the lack of basic administrative support to organise them but also as a smaller pot of money meant clinicians' organisations could not be compensated for their attendance. It was perceived that the effect of all of these changes in the network arrangements was reduced clinical engagement and a lack of 'headspace' to think change through.

''I think the funding issue all together is a big barrier to actually find some head space to do what we need to do, to actually think, to get together, to make change. I think everybody's really beaten up in health and social care, to be honest, so it's difficult sometimes to find enthusiasm.''
– GP and Clinical lead for Long Term Conditions, CCG

''Well, I think there needs to be an explicit expectation that resources are put into pathway leadership, and I don't mind where it comes from or who's paying for it, but the expectation and requirement must be there that providers are not just at the coal face, slogging away, doing what they do now. They've got to have some clinical leadership and managerial and informatics support to continuously quality-improve and innovate."
– Chief Medical Officer for Clinical Network

COMMISSIONERS INVESTING IN NEW SERVICES

A number of interviewees talked about the attitude of Clinical Commissioning Groups (CCGs) towards financial husbandry and how their attitude was potentially now more conservative because of their new position as budget holders. The need to 'balance the books' in year was also commented on in relation to CCGs, and how this could impede any long-term 'spend to save' type initiatives.

> "I think CCGs are rightly very cautious about signing up to new investments. Because you know they have to balance the books. They have to demonstrate they are a responsible commissioner that won't overspend on the allocation they're given. So most of the things we've put forward for improving services we don't think are necessarily high cost ...but the challenge is always have they got the money now to pay for this - they've actually got to balance the books in year.''
> – Cancer Commissioning Manager, CSU

Providers seem to understand that CCGs do not have a 'bottomless pit' of money and that they have a range of priorities to consider, only one of which might be cancer. Though this is no different to the situation with the Primary Care Trusts (PCTs), there was a sense that as CCGs often serve smaller populations than PCTs, there was a more 'local' assessment of priorities. This granularity might actually be diluting the attention given to cancer and would subsequently impact on investment in service development and improvement initiatives. In some areas, a single CCG has taken the lead for commissioning cancer services for the other CCGs in its area and this was seen as a positive development in terms of the joining of resources to maintain a focus on cancer.

Interviewees were generally optimistic about the potential of shared commissioning arrangements between CCGs and specialised commissioning to enable commissioning of pathways rather than episodes of care.

> ''The changes that have been mooted by Simon Stevens in terms of shared commissioning and collaborative commissioning is absolutely music to my ears and I think it'll be a great opportunity for cancer services to go back to being pathway-coordinated and managed at a local and regional level, which is good.''
> – National interviewee

> "What's not been integrated, if you like, is the ability to put the levers in place between primary care/CCG priorities and specialist commissioning. ... I welcome the idea that Simon Stevens is saying he wants to get CCGs and specialist commissions to co-commission things together, 'cause I think that would make a big difference."
> – Clinical Director, Network

DEVELOPING NEW MODELS OF CARE

There was a gathering sense of urgency about starting service redesign work now in order to meet the challenges of the years ahead. The ongoing work on molecular genetics was raised as an issue to think more about for the future. Interviewees recognised the potential in terms of greatly improved outcomes for patients but were concerned about the cost of expensive tests and treatments that would result.

> "What will happen is that science will give us more and more genetic information about molecular information about individuals' cancers. And for each individual there will be different targeted therapies that will become available that we can treat them with and that will keep their disease under control for months, years, possibly longer...Now can we afford to develop those treatments? And if we develop them, can we afford to buy them? And I think those are the really big challenges."
> – National interviewee

In the more immediate future, the need for more co-ordinated and joined up care, particularly across primary and secondary care settings was expressed. There was also an emphasis on services working across traditional boundaries to meet complex patient clinical and holistic needs.

> "I would also like to see more integrated working between primary and secondary care with better communication between all health care professionals."
> – GP, with CCG role

"I would like colleagues in secondary care to recognise that managing cancer patients is everyone's business, not just for a few specialists to deal with. Cancer is too common now, and becoming ever more so, to rely on cancer specialists for basic pain management, discharge planning, arranging community support etc. I would like an integrated approach rather than 'cancer is for oncologists to sort out'."
– Doctor, cancer specialist

However, it was noted that the financial situation, the way the market operates and vested professional interests were powerful barriers to change. More support from policy makers was therefore seen as necessary - in both a political and a practical way.

"There are so many different vested interests that it's very difficult to make any change ...there is a will in some places to forego business on the part of a trust that in other places is not going to happen ...There are also professional interests and guarding of territory. (We need) to get the kind of perfect storm where everybody comes together and everybody agrees that some things going to change and that includes the clinicians and the managers."
– National interviewee

"So the financial position of acute hospital trusts inevitably makes them really, really defensive about any change...I worry that the lack of money leads to people bringing the needs of their organisational interests before the patient interests and therefore I think is a significant obstacle to some of this."
– National interviewee

Interviewees talked about developing shared care arrangements with primary care but though the direction of travel was generally agreed upon, there were concerns that the primary care workforce were already feeling the pressure of increased expectations on what they should be able to deliver in the future, with a general shift of activity from secondary care into the community.

''Some of them (GPs) have taken a pay cut which is deeply difficult for morale when you are working harder than you've ever worked in your life... I think doctors are getting quite fed up with the way they're being expected to work and then all you hear about is 'oh well, we'll put that out into the community and we'll take them out of the Acute Trust... But I don't know how they imagine that's going to be done.''
– Cancer Clinical Lead, Strategic Network

SURVIVORSHIP AND FOLLOW UP

The issue of survivorship came out strongly as a theme from this study. Interventions are prolonging life and for many patients cancer is becoming more of a long-term condition than an acute episode of illness. Though people talked about the hugely positive strides that had been made in treatment to enable people to live longer, there was a sense of unease that survivorship as an issue had been lower on the list of priorities for providers and commissioners and that it was becoming increasingly important to address.

"More emphasis on survivorship and that survivorship becomes engrained within the cancer pathway and isn't seen as something we do as an aside."
– Commissioner

This requires a different model of care than that which has been provided to date, with better integration of care between secondary and primary care and more focus on the specialist services that might be required to deal with the consequences and troubling side effects of cancer treatment. There was also recognition that patients should not be treated as a homogenous group, and that the diversity of needs must drive more personalisation and tailoring of care.

"There is a reasonable body of evidence that says that follow up care can be provided in primary care or can be managed through an integrated care model. But ... I don't see any systematic shift to shared follow up care across the different sites. And I think that's a shame, but once again it has significant resource implications. There'd be substantial, there'd be a significant disinvestment needed in secondary care and that's not going to happen."
– National interviewee

"It's still too much that cancer is purely seen as an acute illness. The bits of cancer care that happen in the – you know, outside hospitals, in the community, are still not sufficiently developed."
– National interviewee

''So rather than people kind of stumbling along in an oncology clinic for five years with nobody really knowing what they're doing about follow up, that they go out into the community and they get targeted, highly effective treatment."
– National interviewee

Interviewees also recognised that the increasing success in treating cancer patients created its own challenges for future demand on the NHS.

''So there will be more cancer patients, they will be older, they will be frailer, they will have multiple morbidities, they will have higher expectations... [But] there will be less money in order to support them.''
–National interviewee

"In the old days if you had a metastatic cancer you might be treated for six months, or a year and have two or three CT scans. But if you live with your cancer for 10 years, you're probably having 20 or 30 sets of imaging...and thousands of blood tests, so all of those things add incrementally to the cost of caring for people. I suspect we could use up the entire nation's budget to look after people with malignancy in 20 years' time."
–National interviewee

The issue of patients on follow-up surveillance pathways having their appointments affected by new cancer patients coming into the system was also raised. These new patients are subject to waiting time targets, in a way that surveillance patients are not, and therefore the management of the former might become a more pressing priority. There is anecdotal evidence to suggest for example that when a cancer awareness campaign is running, clinic slots are specifically held to cope with the increased demand from new patients referred by their GPs as a result of these campaigns.

''Some of the patients that were sitting on the surveillance pathway were being pushed back a little bit because of the demand for general colonoscopy services and, as a commissioner, it's really difficult to know what the clinical risk of something like that is. [Resources for colorectal] hadn't increased per head of population since the screening programme started which means that trying to pull more people through screening programmes was really difficult because the money was being absorbed by the people who were already taking up the programme so, in a sense they were causing themselves more pressure by trying to do the right thing and improve the uptake.' (LTC Commissioning Lead, CCG)

The system therefore already seems to be juggling the competing demands of diagnosing and treating new patients and managing existing ones appropriately. Such demands are only likely to increase with more people surviving cancer for longer.

PREVENTION AND EARLY DIAGNOSIS

Interviewees felt that more work needs to be done on prevention and early diagnosis and that this would require both clear leadership and an investment in awareness raising programmes, diagnostic equipment, trained staff and clinical space.

''It takes a lot of effort, a lot of investment and a lot of work all across the system to get the early diagnosis message in and to get it to work and my worry is it will fall back without some push, without some national leadership, some resourcing it will fall back.''
– Public Health specialist

"I think that awareness and early diagnosis is the key factor. We are better at treating patients and assisting them to live longer but too many diagnoses of cancer are on emergency admissions."
– Commissioner

Examples were provided of awareness and prevention initiatives that had been funded by non-recurrent grants and awards. These included the training of care workers to be more aware of the signs and symptoms of cancer in the people they look after – whether the elderly, or those with physical or learning disabilities; the training of GP practice nurses in cancer awareness; and the encouragement of community pharmacists to

engage with their customers more in raising awareness of screening programmes

There was also the view that a more rapid assessment model to speed up diagnosis was desirable. This would inevitably come with resource implications however.

> ''I think we are stuck in a model that was developed a long time ago. The idea to assess somebody's risk of having cancer within two weeks is so incongruent with today's expectations that it's a joke and we should have much more urgent ways of assessing people."
> – National interviewee

CENTRALISATION

Views on centralisation were mixed - there were advocates for further centralisation to improve outcomes but also concerns that there had already been too much centralisation at the detriment of providing high quality local services. This alternative view was given in the context of an increasing number of people living with, and beyond, cancer, many of whom would be older.

> "More centralisation is the only way to get better results."
> – Doctor, cancer specialist

> "Less centralisation. At present the push seems to be for more centralisation but with no firm evidence of improved outcomes. This leads to local deskilling and loss of support services which negatively impacts on patient care."
> – Doctor, cancer specialist

> "I think you know it's important to maintain local cancer services in local hospitals, where it's appropriate to do that. And you know I wouldn't want to see everything centralised, because I'm not convinced that's a great patient experience."
> – CSU Cancer Commissioning Team Manager

Increased travel time was raised by some as a negative effect of centralisation, and one that needed further consideration and specific services were identified as being important to deliver as close to the patient as possible, including rehabilitation services and chemotherapy.

> "[More] care closer to home with community based services i.e. chemo."
> – Commissioner

> "I'd like to see more services closer to home" – Patient

DATA MANAGEMENT

Praise was given to the development of new datasets and new connectivity between data sets but caution was also expressed that the existence of these resources was only valuable if the capacity and expertise were also available to make the most effective use of them.

> "In the UK, we have fantastic data sets, far advanced of anywhere else in the world... But they're not well resourced, so we don't have easy access to data ... that's hugely difficult and hugely hampering in terms of being able to go forward."
> – National interviewee

> "I think the SACT, which is the Systemic Anti-Cancer Therapy Dataset, has the ability to hugely influence what we do because it'll be the most comprehensive database of chemotherapy in the world. And we will be able to get an awful lot of outcome information which will tell us whether the things we're doing are as good as we think, or worse than we think... [But] SACT is relatively under invested in terms of our ability to analyse it, so investing in the ability to interrogate all of the information systems that we're developing is important."
> – National interviewee

The move of the Cancer Registries into Public Health England (PHE) was not seen as a positive change for interviewees who commented on this particular aspect of the reforms. People thought there was a lack of capacity and a lack of cancer expertise within PHE to maximise use of the available data that had been collected. Complaints were also made about a lack of access to prevalence data and a delay in the release of survival data.

> "I think the changes for cancer registration going to Public Health England ...in terms of

releasing data to the NHS and helping to drive mprovements through analysis of data ... hasn't been easy and I think some of the traditional access routes have dried up ...So I think ...some of the structural changes haven't helped in terms of flows of information around the NHS, you know, benchmarking and those sort of things."
– CSU Cancer Commissioning Team Manager

"...and it's impossible, at the moment to produce good information because we can't get the prevalence data; the survival data is only just about to come out now, and we wouldn't have seen it in... 18 months to two years, because of the delays and the changes and staff losses, etcetera – they've had a huge haemorrhage of staff across Public Health England...and so that has impacted the information flow ...So that's an example of where it has been absolutely horrendous, the hiatus that the changes have left."
– Medical Director, Clinical Network

"Whilst there have been really good developments in the eight English cancer registries have all been merged on to a single IT platform with common methods of data entry and quality assurance, which is fantastic. The number of people working on cancer, both cancer registration and analytical level, if you add up the numbers that were there before the move to Public Health England and the numbers afterwards...there has been a significant fall in the capacity,''
– National interviewee

DISCUSSION

The NHS in England is struggling to meet current demand and the system is juggling the competing needs of diagnosing and treating new patients and managing existing ones appropriately. This will only accelerate with more people expected to survive cancer for longer and increased screening and early diagnosis initiatives identifying new patients.

Serious doubts were expressed about the ability of the NHS to meet these future demands and deliver improvements in cancer services. It was acknowledged that 'tinkering around the edges' will not deliver the fundamental changes to the design and delivery of services that is undoubtedly required to make services fit for the future. Though there is certainly no appetite for radical restructuring, there is an appetite to do things differently and people appear generally receptive to working in new ways, such as shared care arrangements. However, two main issues appear to be holding people back – firstly, the lack of 'headspace' to think the change through strategically and secondly, the practical support and resources on the ground to make change a reality.

Short-term, non-recurrent funding for development work was raised as an issue by a number of interviewees. One interviewee talked about a survivorship pilot that had been running but was unlikely to be supported longer term by the CCG because of financial constraints, while another was concerned that some innovative work undertaken in their area might not be sustainable because it had been funded by a one-off pot of money and it would need investment from somewhere else to continue. It appears particularly difficult for CCGs to undertake meaningful medium to longer-term planning for services at a local level while they continue to be required to manage their budgets in year.

Not all development and improvement activity is about large-scale strategic shifts. Impact can be achieved by simple solutions, but even so, sustainable funding is crucial. The infrastructure to support the sharing of good practice and innovation is also important but has become more difficult, perhaps with the demise of Cancer Networks working at the level at which such examples of good practice might be more readily known and talked about.

RECOMMENDATIONS

6. The Department of Health and NHS England should explore longer-term budgeting arrangements to allow commissioners the flexibility to invest and innovate. For example, CCGs could be allowed to carry a percentage of their budget over a three-year period to allow genuine outcomes-based commissioning rather than short-term contracting, and time for long-term cost savings to be realised.

7. Commissioners at a national and local level should work together to make realistic long-term plans to meet demand for cancer services, taking account of future expected developments such as longer-term care and personalised medicine. CCGs and other local commissioning bodies should actively seek opportunities for greater collaboration, for example through co-commissioning or lead commissioner models.

8. The Department of Health, NHS England and Public Health England should ensure they truly harness the power of data to drive improvements in cancer care. Investment should be made in the capacity and capability to collect and analyse data effectively and in real time, to realise the opportunity that data gives and ensure the NHS matches outcomes of the best countries in the world.

CONCLUSIONS

The over-riding impression from these findings is that the hard won improvements and momentum in developments that have been evident in cancer services in England over the last 15 years or so must not be lost as a result of the constraints imposed by efficiency savings or the confusion that has ensued as a result of the reforms.

Increasing levels of activity combined with the financial squeeze is certainly being felt within cancer services, and although services have been holding up well, the cracks are beginning to show, as the drop in achieving the 62 day waiting standard demonstrates. Capacity is a concern for staff, not only on a day-to-day basis but also for the future as increasing numbers of people requiring care will inevitably put further demand on services across the pathway. A formalised planning exercise to map demand in the short-term and the medium to long-term future would help to determine where the greatest strain is being felt and where investment is most needed.

There is a significant level of confusion about who does what within the new architecture and a lack of clarity about where responsibility and accountability for this sort of work should lie. And though there are signs that the national Clinical Reference Groups can make a positive contribution to the cancer agenda, there is also a desire for cancer to have a more robust leadership infrastructure in place that can deliver a more co-ordinated response to current challenges across the many different elements of the system and that can also be a force for driving future service developments.

The current system needs to work better for people, and as a minimum the roles of existing organisations need to be better defined and understood, and appropriately resourced to do the job that is expected of them.

This will become increasingly important in order to meet the challenges ahead. A bold approach will be required to develop new models of care – this means the system needs to create the 'headspace' to think change through and the practical support and resources to remove the barriers that are currently proving problematic for people trying to effect change on the ground. For example, the financial planning cycle of Clinical Commissioning Groups and the way in which activity is paid for needs to be considered carefully in order that service development is not unduly hampered by such factors.

A restated common purpose and vision for cancer services in the future is needed, together with a strong political and service commitment and appropriate resources to enable the vision to be achieved. This is no more than patients and staff deserve.

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APPENDIX 1: METHODOLOGY

OVERVIEW

In November 2012, Cancer Research UK published a report, Cancer Services: Reverse, Pause or Progress? (Cancer Research UK, 2012), which looked at the impact on cancer services of the structural changes in the NHS, brought about as a result of the reforms which fully came into force on April 1st 2013, and the financial constraints resulting from the "Nicholson challenge" - a target of £20bn of efficiency savings to be made by 2015. The report noted genuine concerns about the future for cancer services given the uncertainty and disruption caused by widespread system change.

Cancer Research UK subsequently commissioned a new study to build on the 2012 report and to evaluate the ongoing impact of the reforms and efficiency savings. This second evaluation has focused on:

- **Whether cancer services are improving or deteriorating as a result of the changes**
- **Whether the concerns and doubts raised by the earlier report are being confirmed or disproved**
- **How leadership and accountability are evolving within the new system**
- **The effectiveness of the new commissioning architecture**
- **Whether there are any new opportunities or challenges emerging**
- **The factors that will sustain improvements in cancer services**

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). It is difficult – if not impossible – to fully disentangle, isolate and independently assess the effects of the many changes that have affected the commissioning and delivery of cancer services.

This is particularly the case when trying to disentangle the impact of the Reforms versus efficiency savings.
In order to address the questions set, a mixed methods approach was taken comprising of three main elements:

1. **Analysis of routinely available datasets on cancer services performance and cancer expenditure from April 2006 to March 2014**
2. **Exploration of the experiences and perceptions of local and national stakeholders regarding the implementation of the health reforms and efficiency savings through semi-structured qualitative interviews**
3. **A mixed methods online survey reporting stakeholders' views of specific elements of the Reforms and efficiency savings**

ANALYSIS OF QUANTITATIVE DATASETS

Published data for the periods April 2006 to March 2014 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.

Additionally, publically available NHS programme budgets for the years 2006-07 to 2012-13, were analysed[6]. This review consisted of:

- **The measurement of the year-on-year growth/decline in the overall budget in both nominal and real terms over the seven years. This provides background information on the**

[5] At the time of publication, aggregate data for 2013/14 was not available

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. This proportional analysis describes how cancer services compete with other demands on the budget.
- A description of the total expenditure on cancer services by care setting.

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 five case study sites, determined by the boundaries of NHS England Local Area Teams. The selection of sites 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 area characteristics:

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

A total of 45 people took part in telephone interviews between April and June 2014. Interviewees were selected to ensure a variety of different roles and perspectives and the final sample included the following; Service providers – both clinicians and managers, commissioners – both Clinical Commissioning Groups and Clinical Commissioning Units, Local Area teams (the regional bodies of NHS England), clinical network and Clinical Senate staff, GPs, public health experts and patient representatives.

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.

ONLINE SURVEY

A key element of the study was an online survey to provide further insights into the nature, scale and extent of changes sparked by the NHS reforms. A mixed-methods survey was created, combining closed response (quantitative) and free text (qualitative) questions. The survey started with a series of fixed response questions probing specific issues – such as service improvement, commissioning arrangements, local leadership and the workforce – before moving on to ask respondents to rate the impact of the reforms and current financial context on cancer services. It finished with two open questions enabling participants to share more general thoughts, including reflections on the future of cancer services.

The survey was distributed through:

1. The memberships and professional networks of several leading organisations and charities. These were the British Gynaecological Cancer Society, Thyroid Cancer Forum UK, BASO – The Association for Cancer Surgery, Breast Cancer Care Nursing Network, Prostate Cancer UK Health Professionals Network, Association of Cancer Physicians, British Association of Head and Neck Oncologists, UK Oncological Nursing Society and British Psychosocial Oncology Society.

2. Direct contacts of the research team and Cancer Research UK. This included contacts in the National Cancer Intelligence Network,

National Cancer Research Network and National Cancer Research Institute.

3. Emails sent to a named contact in every CCG, Area Team and Local Medical Committee in England.

A covering email including a link to the online survey was sent out explaining the purpose of the survey and encouraging responses from anyone involved in planning, delivering and/or improving cancer services. The email explicitly mentioned that this included secondary care doctors, GPs, nurses, allied health professionals, managers, public health practitioners, policymakers, CCGs, CSUs and Area Teams.

A snowballing technique was employed, whereby participants were encouraged to forward details of the survey to their colleagues and contacts. An advantage of this approach is that the reach of the survey is maximised, as people not known or accessible to the team may be encouraged to participate in the survey. However a drawback of this methodology is that there is no way of knowing the size of the overall survey population; as a result the response rate cannot be reliably determined.

A total of 465 responses were received from a wide range of participants. The table below shows the number of responses by job role. The group we have termed 'Other' includes respondents from a range of areas including social workers, multidisciplinary team co-ordinators, and patients and carers.

Table 2: Number of responses by job role

Role	Number of responses
Doctor – cancer specialist	153
Doctor – other	26
Cancer nurse specialist	79
Nurse – other	25
Public health practitioner	6
Provider organisation: non-clinical manager	14
Provider organisation: clinical manager	1
GP	6
GP with CCG role	29
Commissioner	21
Commissioning support	7
Allied health professional	58
Other	40
Total	**465**

APPENDIX 2: INTERVIEW TOPIC GUIDE

QUESTION 1. (5 MINS)

Aim: Capture background information about the interviewee.

Main question: Can you start by telling me a bit about your current role and main responsibilities in terms of cancer services?

Possible probes:

- How long have they been in current position?
- Has their own role changed as a result of the reforms?

QUESTION 2. (10 MINS)

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 your area at present?

Possible probes:

- Effects of centralisation/reconfigurations/ service redesign?
- Views about changes in prevalence/effects of demographic changes?
- Adoption of new technologies/treatments/ interventions? And patient access to these?
- Investment/financial constraints?
- Progress on prevention, awareness and early diagnosis?
- Workforce – capacity and capability?

QUESTION 3. (10 MINS)

Aim: Explore perceived ongoing impact of the health reforms and efficiency savings on cancer services locally.

Main question: From your experience, how have the reforms impacted on cancer services? How have efficiency savings impacted on cancer services?

Possible probes:

- Have any previously perceived threats/fears faded away?
- Have negative impacts been mitigated against, and if so how?
- Have earlier fears of negative impacts started to have real effects? (e.g. fragmentation)
- Is their organisation gathering any data/ evidence that shows these effects?
- Has there been any impact on patients as a result of the reforms/efficiency savings?

QUESTION 4. (5 MINS)

Aim: Explore the perceived situation as regards national and local system leadership and accountability for the delivery of cancer strategy and services

Main question: Is it clear to you who is providing national leadership for the delivery of cancer strategy and services?

Is it clear to you who is providing local system leadership?

Who is accountable for the effective and efficient delivery of cancer services locally?

Possible probes:

- What role does NHS England have in leadership terms?
- What role does their Local Area Team have?
- Has the abolition of cancer networks had any impact locally?
- How well are their local clinical senates and strategic clinical networks working?
- Are Health & Wellbeing Board(s) playing a role in the commissioning or delivery of cancer services?

QUESTION 5. (5 MINS)

Aim: Explore the effectiveness of the new commissioning architecture created by the reforms

Main questions: Is the expertise and experience in place in your local area to commission cancer services effectively?

Possible probes:

- **How are local Clinical Commissioning Groups working? (Support from local CSU/LAT?)**
- **Has the nature of the relationship between commissioners and providers changed as a result of the reforms? If so, in what ways and how has this affected cancer services?**
- **Have the reforms had any impact on performance managing local providers?**

QUESTION 6. (5 MINS)

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

Main question: How would you like to see cancer services develop in your area over the next five years?

Possible probes:

- **What is needed in order to realise their vision? (Role of research? Role of Public Health?)**
- **What are the main challenges to realising this vision? (Any workforce issues?)**
- **What do they see as the priorities for investment?**

QUESTION 6. (5 MINS)

Aim: Gather any further suggestions/insights that may add to the research

Main questions: Is there any particular message regarding cancer services that you would like to be heard at a national level?

Is there anything else you would like to add that you think may be helpful or informative to this study?

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