CAPACITY TO DIAGNOSE?

AN ANALYSIS OF CANCER DIAGNOSTIC ACTIVITY IN ENGLAND

MARCH 2018

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2 EXECUTIVE SUMMARY

BACKGROUND

Earlier diagnosis of cancer can save lives and avert treatment costs. It is critical to improving cancer outcomes in England, and the cancer strategy suggests investing now to drive improvements in earlier diagnosis can lead to savings for the NHS in future. It is in the interests of patients, clinicians and the NHS to make rapid progress on diagnosing cancer earlier.

Yet the evidence suggests that cancer patients in England are often diagnosed at a later stage than patients in comparable countries. ^{1,2} A key theme of the cancer strategy, <u>Achieving world-class cancer outcomes, a strategy for England 2015-2020</u>³, was therefore diagnosing patients earlier. It proposed a number of initiatives to achieve this. Many of these will require increased diagnostic activity, such as updated NICE referral guidelines for suspected cancer. ⁴ These guidelines lower the threshold of suspicion before people are referred to a specialist or for diagnostic tests and therefore lead to an increase in activity. ⁵ Diagnostic services are essential to diagnose and monitor a huge range of conditions so boosting capacity will also benefit other diseases beyond cancer.

However, an increase in diagnostic activity requires more staff and equipment, and more funding to support these. The cancer strategy recognised that pressures on diagnostic services limits the ability for large increases in investigative testing to be made and that the implementation of the new NICE guidelines will not be a success without a "significant injection of resource to improve capacity". 6 Without the equipment and trained personnel, the aspirations of the cancer strategy will not be met.

Cancer Research UK welcomed NHS England and the Government's 2015 commitment to increase funding for diagnostic capacity. This included 'up to £300m more on diagnostics every year' by 2020. Growth was modelled (for the Five Year Forward View) as a 7% increase in overall diagnostic activity year on year to 2020/21. The 7% increase was part of clinical commissioning group (CCG) allocations in the baseline funding for CCGs. ^{8, 9} It is important to note that neither the £300m increase, nor the 7% activity projections are likely to fulfil the growth in cancer diagnostics.

Nationally, this modelled growth and CCG planning guidance suggests that diagnostic capacity is a top priority. However, at a time when NHS finances are increasingly stretched and there are numerous competing priorities, including improving A&E performance, there is a danger that when faced with local realities, resources will not be spent where they are intended. There is also a risk that this modelled growth is not sufficient to meet demand, and that waiting times targets (showing the mismatch between capacity and demand) will be missed.

Although all areas of England are likely to need to increase diagnostic activity, the analysis in this report (echoing the findings of the Atlas of Variation¹¹) shows there is substantial variation in levels of activity. It should be noted this variation has not been adjusted for different population characteristics so may be clinically appropriate. All areas would be expected to see increases over time due to an ageing and growing population, more comprehensive implementation of NICE referral guidelines and other drivers of increased activity. Halfway through the duration of the cancer strategy, it is timely to assess the

progress made to increase diagnostic capacity, the extent to which these variations in diagnostic activity persist, as well as the areas where action is still required if the NHS is to deliver on the ambitions it has signed up to through the cancer strategy.

AIMS

This report:

- analyses activity levels (and waiting times, which can show where demand exceeds capacity)
- assesses the extent to which resources allocated to increase diagnostic activity are being used for that purpose
- explores why this might not be happening
- makes recommendations to support national government and NHS England to meet the ambitions of the cancer strategy.

METHOD

The report draws on a range of information sources, including publicly available datasets and responses from 106 CCGs to a survey conducted between April and June 2017. It also recognises the context in which diagnostic services are operating in – such as the capped expenditure process potentially reducing spend on diagnostics, and the use of referral management centres.

The tests analysed in this report are:

- Imaging (barium enema, CT, fluoroscopy, MRI, medical photography, non-obstetric ultrasound, nuclear medicine, PET/CT, SPECT, Xray)
- Endoscopy (colonoscopy, cystoscopy, flexible sigmoidoscopy, gastroscopy, urodynamics)
- Histopathology

These tests were chosen due to their relevance to cancer diagnosis, although they may also be used when there is no suspicion of cancer, to characterise a cancer when a diagnosis has been made, or as a surveillance tool to assess a patient's progress.

Limitations in the data mean that it is not possible to determine what these tests were ordered for but they are likely to reflect, in part, an increase in cancer diagnostic activity. It is also not possible to distinguish the contribution that tests due to cancer screening programmes have made.

Due to the differences in funding, structures and data across the UK, the analyses and recommendations in this report are specific to England.

KEY FINDINGS

DIAGNOSTIC ACTIVITY HAS INCREASED NATIONALLY, BUT THERE IS LOCAL VARIATION

Nationally, diagnostic activity is increasing. For example, over 4.6 million more imaging tests were performed in 2015/16 compared to 2012/13. Although these tests are regularly used to diagnose cancer, many have wider clinical uses. For example, imaging may be used for musculoskeletal, cardiovascular or any number of other symptoms, diseases and conditions. But a significant proportion of this activity will be cancer-related.

Although diagnostic activity has increased in most CCGs, there is substantial variation. For example, since 2013/14, some CCGs have reported an increase in CT activity of 6.2% per capita, whereas others have reported a reduction of 2.1%. The reasons for these discrepancies are unclear and could be the result of different factors, including changes to populations, issues with equipment, staff shortages, local service configurations or CCG boundaries.

WAITING TIMES PERFORMANCE SUGGESTS THERE MAY STILL BE ISSUES WITH CAPACITY

Waiting times for tests have increased substantially, suggesting that capacity and activity are not keeping pace with demand. Routine diagnostic waiting times are not specific to people with suspected cancer, but around a quarter of all people diagnosed with cancer will come through a 'GP referral' route, which is likely to include routine referrals.

During 2016/17, an average of nearly 10,000 (9,642) patients every month waited for longer than six weeks for a routine diagnostic test. This is an increase of 130% on the number in 2008/9. This may not be reflected in missed waiting times targets (for 99% of people to receive a diagnostic test within 6 weeks) if the overall number of tests has also increased as it may remain relatively stable as a proportion.

During this same period, the number of people being referred for a test rose by 111%. This suggests that increases in demand are not the sole explanation for missed waiting times as the proportion waiting is greater than the increase in referrals – there may also be problems with capacity or efficiency.

Long diagnostic waiting times appear to be endemic in some CCGs. For example, several CCGs were amongst the poorest performing for a variety of different tests.

CCGS ARE AWARE OF NATIONAL COMMITMENTS TO ENSURE 'ADEQUATE DIAGNOSTIC CAPACITY' BUT THERE ARE VARYING APPROACHES, INCLUDING SOME REDUCTIONS

Nine in ten (89%) CCGs responding to our survey were aware of the NHS England 2016/17 planning guidance 'must do' to ensure "adequate diagnostic capacity".

Despite the additional resources allocated to CCGs, 29% of respondents that provided budget allocations for diagnostics in 2015/16 and 2016/17 (n=7) reported a decrease in the amount allocated between these years. Some CCGs that reported reduced allocations were unable to provide data on activity or waiting times.

CCGs were asked to provide information on plans they had to improve and expand diagnostic capacity in 2017/18. Nearly a third (30) of responding CCGs could not provide this information either because plans were not recorded formally or because they had no plans to expand capacity beyond existing levels. Of these, two thirds (22) said that the CCG did not intend to increase capacity in 2016/17, despite national guidance and the uplift in funding.

But there are some encouraging examples of CCGs playing an active role in designing new approaches to streamline diagnostic pathways and enable significant increases in activity.

HOWEVER, CCG DATA ON ACTIVITY, WAITING TIMES AND BUDGETS FOR DIAGNOSTICS IS NOT COMPREHENSIVE

Responding to the survey, very few CCGs reported holding comprehensive information on diagnostic activity and waiting times. There are also some significant discrepancies between CCG data and national datasets, meaning some commissioners may be unable to accurately assess health needs, monitor performance and ensure value for money.

CCGs responding to the survey held largely patchy information on expenditure on tests relevant to cancer. Only one quarter (26%) of respondents were able to provide full information on budget allocations for diagnostics.

Very few (12%, 13) CCGs provided budget allocation forecasts for 2017/18. Of these, some are planning to reduce allocations.

RECOMMENDATIONS

Based on the findings in this report, we make a series of recommendations to ensure that additional resources are devoted to diagnostic capacity. These should be allocated as originally intended. Data should improve for the planning, delivery and accountability for diagnostic tests relevant to cancer.

Cancer Alliances should:

- Work with CCGs, STPs and providers to undertake a review of current and future diagnostic activity relevant to cancer.
- Identify within their Alliance any significant variations in activity between CCGs, investigate the reasons, and agree a published action plan to address any unwarranted variation.
- Review the commissioning of referral pathways to ensure they meet national guidance, such as the NICE recognition and referral guidance for suspected cancer or the National Optimal Lung Cancer Pathway.
- Highlight where future demand may exceed capacity to inform national funding and workforce plans.
- Share their diagnostic activity forecasts with Local Education and Training Boards (LETB) and Local Workforce Action Boards (LWABs) to inform local workforce plans.
- Explain where and why CCGs have not met the 7% increase in activity.
- Audit the impact that referral management centres have on cancer diagnoses and take corrective action if necessary.

NHS England (including the National Cancer Programme and Directors of Commissioning Operations) should:

- Publish an update to demonstrate progress made on increasing diagnostic capacity.
- Use CCG and alliance analyses to hold CCGs to account on meeting planning guidance.
- Make it clear (alongside NHS Improvement) that increases in diagnostic activity should not be compromised by the new Capped Expenditure Process. The financial processes required to implement the Capped Expenditure Process should be considered as a means of ensuring that funding is deployed for the purpose that it was initially allocated, as well as to control overall costs.
- The use of additional funding for diagnostics could be monitored using a similar system to the Mental Health Investment Standard¹⁴, set out in 2018/19 NHS planning guidance. This says that CCGs' auditors will evaluate their 2018/19 year-end position to show investment has risen at a faster rate than overall programme funding.

Health Education England should:

• Use information from CCGs and alliances on their workforce needs to inform national action, such as increasing training places or coordinating post-graduate training.

The Department of Health should:

- Ensure that funding for diagnostic capacity is sufficient to meet future demand, and if
 not, increase and ring-fence this additional funding so it can be clearly demonstrated
 that it has been used for its intended purpose. This was a Government commitment so
 requires oversight from DH.
- Reassess capital investment requirements for diagnostics and consider the case for further investment to support increases in activity. This is timely in the context of the Department of Health's intention to develop a new capital strategy and the Government's manifesto commitment to "introduce the most ambitious programme of investment in buildings and technology the NHS has ever seen."

NHS Digital should:

- Improve diagnostic datasets so that the purpose and finding of an investigation is recorded, as well as the test that is undertaken. New national datasets should be implemented to record activity for endoscopy and pathology, to enable effective planning and commissioning of services. This is building on existing work to create a national endoscopy database and similar work on pathology. 15
- Work with CCGs to understand why some discrepancies occur between the figures in nationally reported data and locally held information on diagnostic activity and ascertain the true picture.

CONCLUSION

We welcome efforts from the Government and the NHS to diagnose cancer earlier – but these can be improved further with more scrutiny on how additional resources are deployed. The additional resources to boost diagnostic capacity should be used as originally intended. Increasing diagnostic capacity underpins all efforts to diagnose a greater proportion of people at an earlier stage. More diagnostic staff and kit means that initiatives like Be Clear on Cancer, NICE's NG12 referral guidance, the 28-day Faster Diagnosis Standard and improvements to bowel and cervical screening have a better chance of success. And in future, better data should improve the planning, delivery and accountability for diagnostic tests relevant to cancer.

3 INTRODUCTION

Early diagnosis is crucial to improving cancer survival. Treatment is more likely to be successful for cancers that are diagnosed at an early stage. For example, more than 90% of patients diagnosed with the earliest stage bowel cancer survive their cancer for at least five years, compared with less than 10% for those diagnosed at the most advanced stage. ¹⁶ Earlier treatment is also often less invasive or toxic, reducing side effects or long-term consequences and therefore improving quality of life.

In addition, late diagnosis can lead to avoidable morbidity and mortality and can be associated with more expensive treatment costs. Analysis conducted by Incisive Health on behalf of Cancer Research UK in 2014 revealed that if all geographical areas achieved the level of early diagnosis comparable with the best in England across four types of cancer, it could avert £44 million in treatment costs and benefit over 11,000 patients.¹⁷

Evidence from the International Cancer Benchmarking Partnership shows that primary care services in England have a lower propensity to refer when investigating potential cancer than jurisdictions with similar health systems and this has been associated with poorer outcomes. Strain on diagnostic capacity in the UK was seen as a key reason for this. Action has been taken to lower the threshold of suspicion for referral by GPs via NICE's updated recognition and referral guidance (NG12), meaning that even more people should now be investigated.

Yet, achieving earlier diagnosis through lowering the threshold for investigation is dependent on the necessary diagnostic capacity. Without this, the number of people waiting longer than waiting times standards will increase further, as recent trends show more people who have experienced 'missed' waiting times. Limited capacity potentially delays the diagnosis of people with symptoms and as part of their 'gatekeeper' role, might discourage primary care professionals from making referrals²⁰. Capacity could be released in part through better use of existing resource and streamlining pathways. But with growing demand, additional staff and equipment will still be needed: this needs additional funding.

It is now over two and a half years since the five-year *Achieving World-Class Cancer Outcomes* cancer strategy was published. With a new government in place and NHS organisations half way through the *Five Year Forward View*, now is an appropriate time to assess the gap between current levels of diagnostic activity and the evidence-based ambition of diagnosing a greater proportion of cancers at an early stage. In addition, it is an opportunity to scrutinise the effectiveness of initiatives to increase diagnostic capacity and consider what more might need to be done to ensure patients have timely access to diagnostic tests.

As part of delivering the cancer strategy, NHS England:²¹

- Established a National Diagnostics Capacity Fund to "support commissioners and providers to increase diagnostics capacity"
- Increased CCG funding allocations to support the 7% growth in overall diagnostic activity modelled year on year to 2020/21, as per the Government's 'up to £300m more per year'²² commitment to increase diagnostic spending

- Required CCGs to plan for appropriate diagnostic capacity as one of their nine 'must dos' in the 2016/17 planning guidance²³
- Committed £200m Transformation Funding to Cancer Alliances over two years, in part to diagnose cancers earlier²⁴

These measures are welcome, but they are dependent on CCGs deciding to allocate the resources for the purpose for which they were intended. There are examples where there have been similar issues, with mental health funding not reaching the front line.²⁵

Cancer Research UK therefore commissioned this report to establish if diagnostic activity nationally has increased since 2015 and how CCGs were using the additional resource to fund diagnostic services (or if they were being redirected towards other services).

This report is intended to address these questions and provide a helpful contribution to the ongoing debate about how the NHS can deliver world-class outcomes for all those affected by cancer in England.

It examines (in England):

- Diagnostic activity both nationally, and at a local level; and how it has changed over time to reflect increased funding for diagnostic services
- Waiting times to highlight where they may still be issues with meeting demand
- Responses to CCG survey and interview responses exploring diagnostic activity, waiting times and budgeting

Diagnosing cancers involves a wide range of diagnostic tests. Many different data sources have been used in this report but these sources cannot show:

- Investigations for all possible cancer symptoms
- If a test has been used for an initial diagnosis or surveillance, to assess progress with treatment or potential recurrence or spread of disease
- Whether the investigation was due to a suspicion of cancer
- Whether the investigations led to a cancer diagnosis

Despite these data limitations, the analyses in this report do paint a picture of growing demand and activity, highlighting challenges in the NHS. It is possible that commissioners will have more detailed information they did not flag during the survey. However, these survey findings suggest that the respondents are not familiar or do not have access to data to this level of detail and/or they are not regularly scrutinising it.

4 USE OF DIAGNOSTIC TESTS AND PROCEDURES IN ENGLAND

This chapter:

- Brings together data on different diagnostic tests and procedures which are relevant to cancer
- Examines trends over time and between different NHS organisations
- Assesses activity for diagnostic tests

Where the data are from

The Diagnostic Imaging Dataset (DID) is the central database with information on the imaging tests and scans carried out on NHS patients. DID has been collecting and publishing data since 2012/13. The quality and completeness of data collection may have improved over time and could explain some of the increases in activity that have been reported. There is a wide range of procedures featured in the DID – many will not be relevant to cancer. Others will be used to characterise a cancer rather than provide an initial diagnosis. This report analyses DID until 2015/16, which at the time of writing was the last full year to be published.

As DID only features imaging, other sources must be used for a more complete picture of diagnostic activity. The diagnostic waiting times and activity dataset is collected by NHS England on both a monthly and quarterly basis – see annex A for more details.

Diagnostic activity in England

Diagnostic activity relevant to cancer in England has increased. Figure 1 shows that, from 2012/13 to 2015/16, the number of diagnostic imaging tests performed in England rose by 13%, from 35.9 million to 40.6 million.

Cancer Research UK projects that there will be 12.4 million CT scans and 6.9 million MRI scans in 2023-24, up from 5.2 million and 2.7 million in 2013-14.²⁶ Demand for these scans will continue to grow in England, at rates of 9% per annum or more. Some scenarios predict even faster demand growth for imaging after 2020. Similarly, modelling commissioned by Cancer Research UK suggested that over 750,000 more endoscopy procedures a year will need to be undertaken by 2020 than in 2013/14, an increase of 44%.²⁷

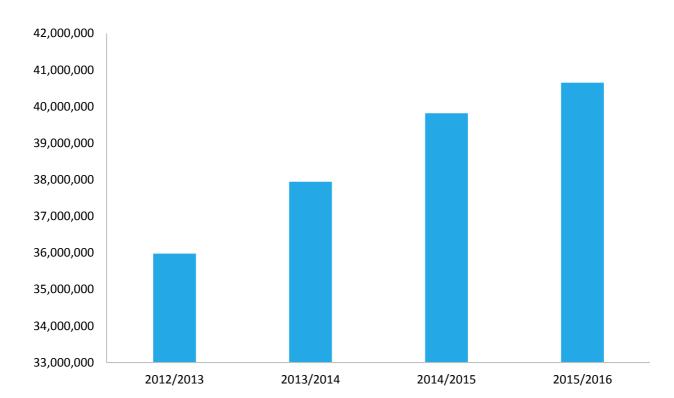


Figure 1: Total number of diagnostic imaging tests in England (CT, ultrasound, MRI, fluoroscopy, medical photography, nuclear medicine, X-ray, PET, SPECT)²⁸

Source: NHS England, Diagnostic Imaging Dataset

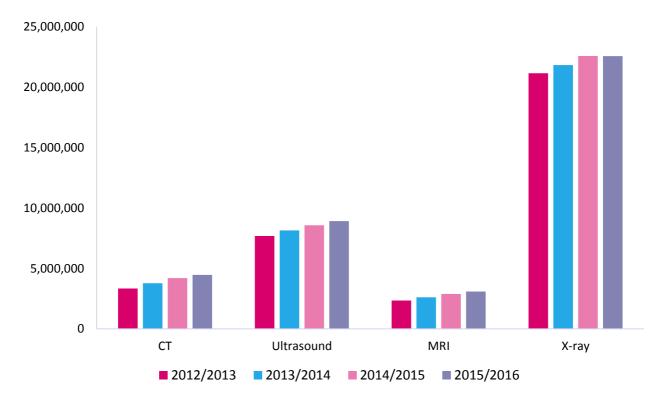
It is likely that this previous increase in activity is driven by a range of factors, including:

- A growing and ageing population. Since 2012, the population of England has increased by 1,774,400 and the most of these people are older as the number of people over the age of 55 has increased by 1,068,400. Given that the risk of most cancers increases with age, it is fair to assume that a growing older population has resulted in increased demands for diagnostic investigations, and that these demographic trends will continue to increase demand.^{29 30}
- A more proactive approach to cancer investigations. The number of urgent referrals
 under the suspected cancer pathway have been going up since 2009, when the Cancer
 Waiting Times dataset was introduced.³¹ The NICE recognition and referral guidelines for
 suspected cancer may have added additional pressures from 2015/16. This is because
 they lowered the threshold of risk for GPs to refer someone and supported GPs accessing
 investigative tests directly themselves
- **Greater public awareness about the signs and symptoms of cancer.** Investment in the Be Clear on Cancer campaigns since 2010 has increased public awareness of the signs and symptoms of a range of cancers. Evidence shows that the success of these campaigns has translated into increased presentations and referrals for some types of cancer³²
- More cancers due to modifiable risk factors. The risk of getting cancer can be influenced
 by exposure to things like tobacco or obesity. These are increasing the number of people
 who are projected to get cancer in the future³³

How data are recorded. Although not a driver of more activity, changes to tariff and how
data are recorded could also have played a role in why there appears to be an increase in
activity

Many of these drivers of increased activity are going to continue in future. The demand pattern is not uniform across different tests. Figures 2a and 2b show that nationally there were increases for most tests. For example, from 2012/13 to 2015/16, the number of CT scans increased by approximately 33% from 3.3 million to 4.5 million.

Figure 2a: Total number of tests in England from the Diagnostic Imaging Dataset³⁴



Source: NHS England, Diagnostic Imaging Dataset

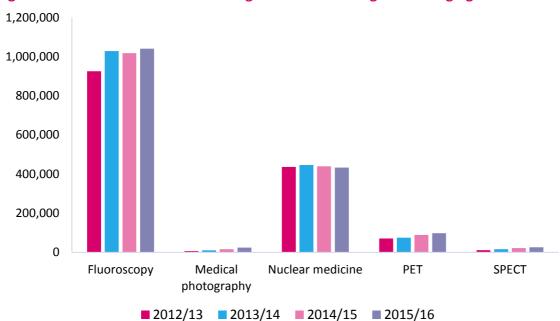


Figure 2b: Total number of tests in England from the Diagnostic Imaging Dataset 35

Source: NHS England, Diagnostic Imaging Dataset

Similarly to the activity growth in imaging, Figure 3 shows that over the period 2008/09 to 2016/17, activity levels for colonoscopy, gastroscopy and flexible sigmoidoscopy rose to their highest levels in 2016/17. Although not shown in Figure 3, activity levels for dexa scans and cystoscopies also followed this pattern. However activity levels for urodynamics in 2016/17 were lower than in 2008/09. Activity was also lower for barium enema, due to the procedure being phased out of clinical practice in recent years.

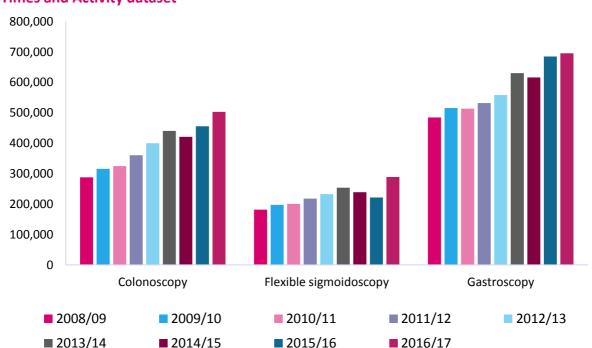


Figure 3: Total number of endoscopic procedures in England from the Diagnostic Waiting Times and Activity dataset³⁶

Source: NHS England, Diagnostic Waiting Times and Activity dataset

Activity by clinical commissioning group (CCG)

At a CCG level, data from most CCGs shows an increase in the volume of diagnostic activity. Figure 4 shows that when CT activity levels are analysed per capita between 2015/16 and 2016/17, activity increased on average across CCGs by 7%. However, within this overall increase there is significant variation. Between CCGs, the change per capita varied from an increase of 38% to a decrease of 43%, with 19 CCGs recording a decrease in activity per capita from between 2015/16 and 2016/17.

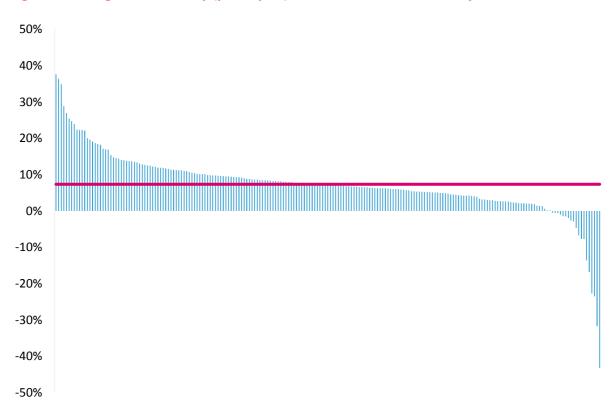
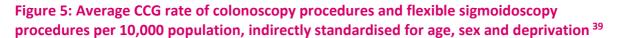
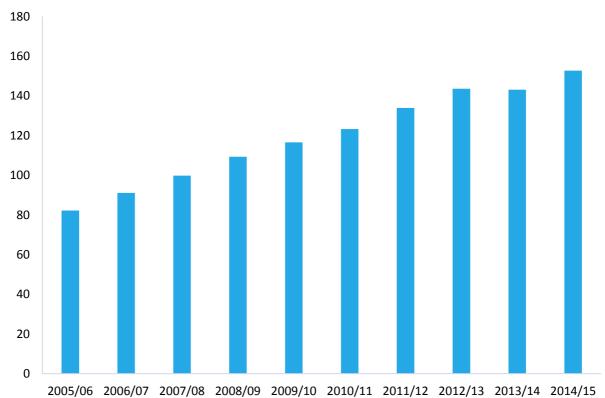


Figure 4: Change in CT activity (per capita) from 2015/16 – 2016/17 by CCG³⁷

Source: NHS England, Diagnostic Waiting Times and Activity dataset

Endoscopy has been identified as a particularly pressing priority for capacity increases.³⁸ This is not surprising given the increase in the number of colonoscopies and flexible sigmoidoscopies since 2005/06. This is likely to be in part due to the introduction of the bowel screening programme. As shown in Figure 5 from the Atlas of Variation, between 2005/06 and 2014/15 the average CCG rate of two types of endoscopy per 10,000 population rose from 82.2 to 152.7, an increase of 85%.





Source: NHS England and Public Health England, the 2nd Atlas of Variation in NHS Diagnostic Services in England 2017

The Five Year Forward view modelling suggested there would be a 7% increase in diagnostic activity each year from 2015/16. The imaging and endoscopy activity changes outlined here suggest that nationally, there has been increasing activity over the last few years. Due to the timeframes for some of the data used in these analyses, it is not possible to categorically say that diagnostic activity has increased by 7% from 2015/16 to 2016/17. However, it is concerning that local snapshots of activity changes suggest the increase in activity is not consistent in all CCGs. This will be examined in more depth in chapter 6.

It is also concerning that while activity has increased nationally, demand may still be outstripping capacity, leading to more people waiting for tests and results. This is examined in chapter 5.

5 DIAGNOSTIC WAITING TIMES PERFORMANCE

Performance against the diagnostic waiting times standard

Analysis of NHS England datasets shows that waiting times for diagnostic tests are getting longer, suggesting that capacity and activity are not keeping pace with demand.

The NHS Constitution states that patients who need a test should not wait longer than six weeks from referral, and NHS England states that this target should be achieved for 99% of patients. 40,41 There are additional and separate standards to deliver tests swiftly for people who are urgently referred for suspected cancer. One example of cancer waiting times standards is the 62-day wait. This sets out that patients should start treatment within two months of receipt of urgent referral with suspicion of cancer. But as the majority of cancer patients are not diagnosed whilst on the 62-day waiting times pathway 42, it is relevant to examine the wider diagnostic waiting times and activity data rather than just cancer waiting times.

Although the data on diagnostic waiting times in 2016/17 show clear signs of improvement, it is notable that there are still long waits for some patients, despite CCGs receiving additional funding to resource more diagnostic capacity. This is due to a number of factors, including:

- Demands on CCGs to meet other performance targets, including the four-hour A&E and the 62 day cancer waiting times standard
- Workforce pressures, including staff shortages and recruitment challenges
- Absence of equipment to carry out tests and procedures
- Revenue spending being insufficient to meet changes in demand or used to fund other areas of healthcare
- More patients requiring tests

Publicly available data on diagnostic tests does not tell us why a test was performed, so it is not possible to examine waiting times for tests for suspected cancer in isolation. Nonetheless, it is possible to examine diagnostic waiting times for tests that are relevant to cancer. The recorded data for diagnostic tests and procedures included in the analysis are:

Test	Possible cancer being investigated
MRI	Brain
СТ	Lung
Non-obstetric ultrasound	Ovarian, womb
Dexa scan	Bone
Urodynamics	Bladder
Colonscopy	Bowel
Flexible sigmoidoscopy	Bowel
Cystoscopy	Bladder
Gastroscopy	Oesophageal, stomach
Histopathology	All solid tumours

Figure 6 shows that during 2016/17, an average of nearly 10,000 (9,642) patients every month waited for six weeks or more. This is an increase of 130% on the number waiting over six weeks since 2008/9. During this same eight-year period, the number of people being referred for a test rose by 111%. Some of these patients may have received their test one or two days after the six- week threshold. However, our analysis shows that on average each month 2,363 patients waited longer than ten weeks for a test. If patients are being diagnosed late then they may receive treatment later and their outcomes could be worse.

As the increase in the number of patients waiting longer than six weeks was higher than the increase in the number of patients being referred, it suggests that greater demand is not the sole explanation for growing waiting times. Growing waiting times indicate a mismatch between the activity that can be delivered (due to capacity constraints) and the demand on a service. Commissioners will also have access to this information by type of test or pathway, which could help to explain where the specific pressure points are and therefore where more capacity or efficiencies are needed. New approaches to pathways may alleviate some pressures – such as the National Optimal Lung Cancer Pathway. A version of this was introduced as part of the Accelerate, Coordinate and Evaluation (ACE) projects, and in one example the time from chest xray to an outpatient appointment to discuss diagnosis was shortened from 27 to 18 days. 43

However, in the short term, between 2015/16 and 2016/17, when commitments to diagnostic capacity have been made, it appears that fewer people have been waiting over 6 weeks. This suggests that focus on increasing diagnostic capacity has had a positive impact on reducing people waiting longer than stipulated NHS constitutional standards.

14,000 10,000 8,000 4,000 2,000 0 2008/09 2009/10 2010/11 2011/12 2012/13 2013/14 2014/15 2015/16 2016/17

Figure 6: Average number of patients each month waiting six or more weeks for a diagnostic test or procedure (all tests)⁴⁴

Source: NHS England, Diagnostic Waiting Times and Activity dataset

Figure 7 shows the average number of patients waiting six weeks or more for each test between 2015/16 and 2016/17. It is welcome that for nearly all of the test types, the average number of people waiting six or more weeks dropped between 2015/16 and 2016/17. The exception to this trend is patients waiting for MRI and CT, where there was a modest increase of 264 patients (MRI) and 255 (CT) waiting for more than weeks as an average per month.

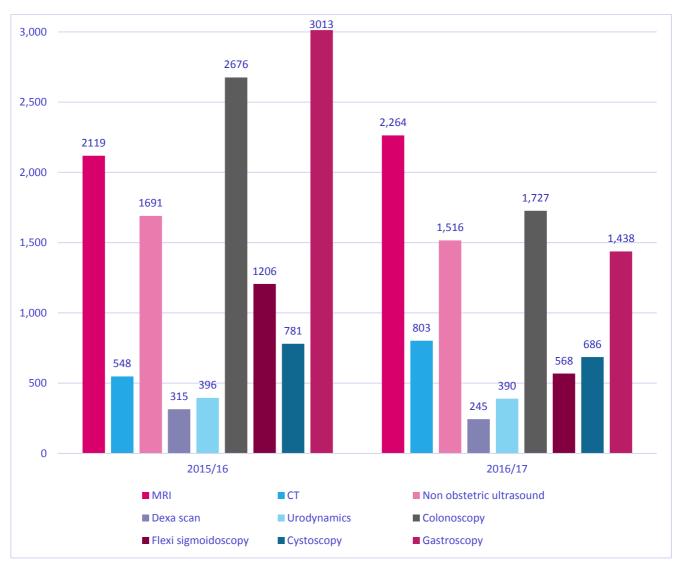


Figure 7: Average number of patients each month waiting six weeks or more (by test)⁴⁵

Source: NHS England, Diagnostic Waiting Times and Activity dataset

Although there has been growth in the level of endoscopy activity across the country over the last ten years, there are some recent, notable successes for endoscopic tests (gastroscopy, flexible sigmoidoscopy and colonoscopy). The number of people waiting more than six weeks for gastroscopy between 2015/16 and 2016/17 reduced by over half (from 3,013 to 1,438 people). Encouraging improvements were also made for flexible sigmoidoscopy, where the number fell by over half (from 1,206 to 568 people), and colonoscopy, where the number fell by 35% (from 2,676 to 1,727 people). Improvements in waiting times for endoscopy tests are a welcome indication that warnings about service pressures for these tests have been acted on, but these pressures will continue in the future.

As well as rising demand for these procedures, endoscopy services have faced wide ranging workforce challenges including issues with recruitment, retention and training – all of which may contribute to a lack of capacity. ⁴⁶ In response to these concerns, in September 2015, the Government announced that 200 additional staff would be trained to carry out endoscopies by 2018 to help address these pressures. ⁴⁷ In December 2017, the first Health Education England cancer workforce plan pledged an additional 200 clinical endoscopists. ⁴⁸

These pressures were apparent with the increase in the number of patients missing the sixweek target for endoscopies from 2008/09 to 2016/17, as shown in Figure 8. During these years the number more than doubled, reaching an average of 3,733 patients every month. However, improvements have been made between 2015/16 and 2016/17, with 3,162 fewer patients missing the target each month.

 8,000

 7,000

 6,000

 5,000

 4,000

 3,000

 2,000

2015/16

Figure 8: Average number of patients each month waiting six weeks or more for an endoscopy (colonoscopy, flexible sigmoidoscopy, gastroscopy)⁴⁹

Source: NHS England, Diagnostic Waiting Times and Activity dataset

2008/09

1,000

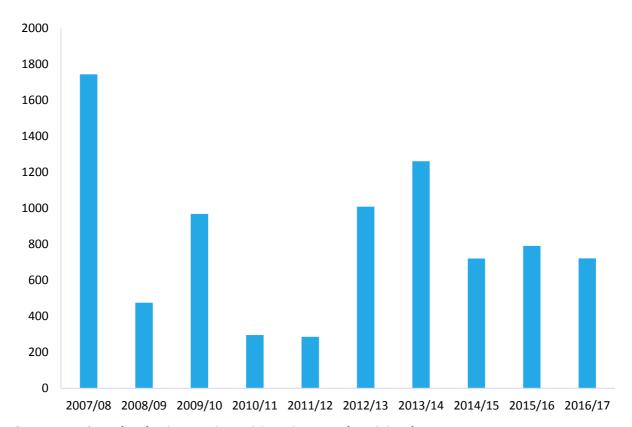
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2016/17

Figure 9 shows the average number of patients waiting six weeks or longer for histopathology at the end of each quarter. It shows that the average number waiting six or more weeks dropped from 1,745 in 2007/08 to 722 in 2016/17, a reduction of 59%, and by 43% between 2013/14 and 2016/17 (from 1,262 to 722).

Although the data does not tell us how many patients received a test each year in total, it is promising that the delays have reduced significantly since 2013/14 even though demand is likely to have risen during the same period.

Figure 9: Average number of patients at the end of each quarter waiting six weeks or more for a histopathology⁵⁰



Source: NHS England, Diagnostic Waiting Times and Activity dataset

Variation in waiting times

The six-week target applies equally to all types of diagnostics. Yet there are significant variations in how long patients wait for different tests, and how they have performed over time (as per figure 7).

Figure 10 compares the waiting times for each diagnostic test in 2016/17. In 2016/17, the 99% target was only met for four of the tests analysed and missed for all endoscopy tests. The number of patients waiting longer than six weeks was over three times higher for urodynamics and endoscopy than for other tests.

9%
8%
7%
6%
5%
4%
3%
2%
1%
0%

Dera scan
Lirodinanic
Colonoscon
Lirodinanic
Colonoscon
C

Figure 10: Average percentage of patients each month waiting six or more weeks in 2016/17 (by test)⁵¹

Source: NHS England, Diagnostic Waiting Times and Activity dataset

Variation by CCG

Figure 11 shows the average percentage of patients in each CCG area waiting six or more weeks for an MRI in 2016/17.

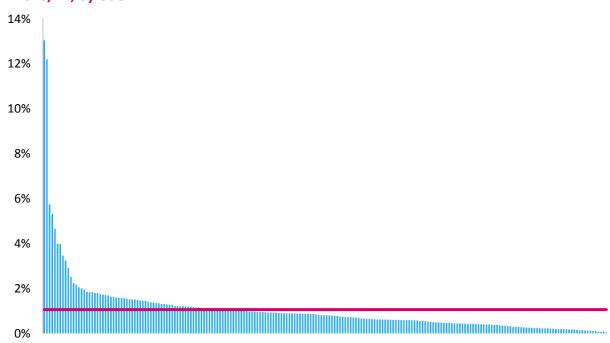


Figure 11: Average percentage of patients each month waiting six or more weeks for an MRI in 2016/17, by CCG⁵²

Source: NHS England, Diagnostic Waiting Times and Activity dataset

The analysis conducted on MRI waiting times in figure 11 was repeated for all test types in the waiting times and activity dataset, which showed that 106 CCGs missed the target for at least one diagnostic test in 2016/17. Of these, some had system-wide challenges:

- 44 CCGs were amongst the lowest performers (defined as the 20 worst performing CCGs) for more than one test
- Two CCGs were amongst the lowest performers for six different tests
- One CCG was amongst the lowest performers for seven different tests

Although this provides a snapshot, a further analysis was conducted on three CCGs that performed badly across six or seven different tests. All three CCGs increased overall in the number of total tests between 2013/14 and 2016/17, by 5,616 tests, 3,588 tests and 1,031 tests.

To give this some context and understand whether the activity pressures on the poorly performing CCGs were greater than for others, three other CCGs were chosen at random from three different regions that were not in the bottom 20 for any test in 2016/17, and their activity levels over time were examined. Like the poorly performing CCGs, these CCGs also increased in overall activity between 2013/14 and 2016/17 by 11,298 tests, 1,184 tests and 1,834 tests. This comparison suggests that the poor performance by CCGs who repeatedly missed the target for multiple tests cannot be solely attributed to increased activity pressures, given that other CCGs experienced similar rises.

Looking more closely into individual tests for the CCGs that performed badly, one of the CCGs performed the worst for two tests in 2016/17 – MRI and CT. From 2013/14 to 2016/17, the number of CT tests increased 3,338, but the number of MRIs increased by only 477.

Next, to see if CCGs that performed badly in 2016/17 had also performed badly in previous years, we focused on two tests, MRI and CT, and looked into how often the CCGs that came in the bottom 20 had also done so in previous years.

Although there is variation, it is clear that some CCGs are repeat poor performers:

For MRI tests, of the lowest performing 20 in 2016/17:

- Seven were not in the lowest performing 20 CCGs for any previous years (2013/14 2016/17)
- Six CCGs were in the bottom 20 three times (between 2013/14 and 2016/17)
- Three CCGs were in the bottom 20 four times
- Four CCGs were in the bottom 20 two times

For CT tests, of the lowest performing 20 in 2016/17:

- Five were not in the lowest performing 20 CCGs for any previous years (2013/14 2016/17)
- Three CCGs were in the bottom 20 four times (between 2013/14 and 2016/17)
- Eight CCGs were in the bottom 20 three times
- Four CCGs were in the bottom 20 two times

It is clear that long waiting times for diagnostics are endemic in some areas of the country. It is also possible these areas of the country have greater population pressures or wider system challenges, including large budget deficits and poor performance against other clinical targets. Further action will be required to address this if the aspirations of the cancer strategy (which committed to improving cancer diagnosis for *all* cancer patients) – and indeed the commitments in the NHS Constitution – are to be met.

6 COMMISSIONING PLANS TO IMPROVE ACCESS TO DIAGNOSTICS

National datasets enable an examination of historical patterns of activity, but they do not enable an understanding of the commissioning decisions made to shape activity, nor of the intentions of commissioners to introduce changes to address these patterns.

CCGs are responsible for commissioning the vast majority of diagnostic tests. This is with the exception of PET scans, which are commissioned by NHS England. This chapter details the findings of a survey of CCGs, examining:

- Their understanding of patterns and volumes of diagnostic activity and waiting times for services they commission
- Allocations of funding to increase capacity and productivity of diagnostic services
- Commissioning plans to monitor improvements in diagnostic services and capacity
- The existence of referral management programmes to assess referrals by local GPs

The survey responses highlighted data quality issues, with inconsistencies in reporting mechanisms, commissioners unable to provide information about local services and unexplained variations in budgets and activity. Some of these data issues were surprising given NHS England requests this information as part of its planning and assurance framework.

106 CCGs responded to the survey. Responding CCGs interpreted the survey questions in different ways and gave responses with varying levels of detail, which may explain some of these discrepancies. It is also possible that the specific responder to the survey may not have had access to the relevant information for their CCG.

To better understand these findings and commissioning behaviour, Incisive Health carried out interviews with representatives from four purposively chosen CCGs which help to inform the conclusions in this chapter.

Prioritisation of cancer

Diagnostic services are an important element of cancer services as a whole. The decisions made by commissioners about the future planning, funding and evaluation of cancer services therefore play an important role in shaping the environment in which diagnostics are delivered, including through:

- Identifying population health need
- Setting the level of priority which should be ascribed to cancer

- Allocating resources to meet identified health need
- Planning for future changes in demand and ensuring that sufficient capacity is available to meet this demand
- Ensuring that national standards are met

We strongly welcomed that NHS England's 2016/17 planning guidance stated "adequate diagnostic capacity" was a 'must do' to help meet NHS performance standards. ^{53, 54} This requirement was repeated in NHS England's Operational Planning and Contracting Guidance for 2017-19. ⁵⁵

As the previous chapter set out, there is still significant work to be done to ensure that diagnostic capacity is sufficient to enable interventions promoting earlier diagnosis and so that tests are timely to enable better patient experience. It is therefore encouraging that almost nine in ten (89%) of the CCGs that responded to the survey were aware of this requirement, and the participants in the CCG interviews confirmed that they each had in place individuals or teams specifically responsible for cancer. Many respondents to the survey stated that diagnostic capacity had been subject to increased investment, or that they had plans to ensure diagnostic capacity was adequate. Responses to the survey and the CCG interviews also revealed examples of encouraging practice:

Examples of local initiatives to increase diagnostic capacity

"Cancer is a high priority within the operational plans for the CCG. This is reflected within the national cancer strategy and also the NHS Operational Planning and Contracting guidance. The CCG is also implementing stratified follow-ups for breast cancer patients invear and addressing emergency presentations with cancer."

One CCG outlined the following steps it intends to make to deliver the NHS Constitution standards:

"Securing additional diagnostic capacity for direct access non-obstetric ultrasound.

Improving one year survival rates by earlier diagnosis, and improvements in the proportion of cancers diagnosed at stages 1 and 2. Reducing the proportion of cancer diagnosed following emergency admission."

Interestingly, the CCG interviews highlighted differences in the levels of confidence CCGs had in their ability to meet rising demand for diagnostic services. One CCG was confident that they had sufficient capacity, but another expressed concern that the current levels of capacity and funding could not withstand further demand pressures, and also raised doubts about the NHS' overall ability to deliver on the cancer strategy's ambitions. CCGs cited equipment and workforce shortages as particular challenges, as well as a lack of capacity to perform the growing number of tests under the two-week urgent referral pathway, with one CCG reporting an increase of a third in the last two years.

Proactive commissioning

Despite this welcome prioritisation, there were clear differences in the level of information held by CCGs to monitor budgets, activity and waiting times.

None of the survey respondents provided all of the information on activity and waiting times that was requested relating to x-ray, ultrasound, CT, MRI, gastroscopy, colonoscopy, flexible sigmoidoscopy and histopathology. Only around one in five (20) provided the figures to partially answer questions on activity or waiting times.

Of the 106 CCG representatives that responded to the survey:

- Fewer than one in ten (10) provided information on both activity and waiting times
- One third (34) were able to provide figures on activity levels
- One in seven (16) held data on average waiting times

Other respondents:

- were not able to provide the information requested
- chose not to provide the information
- referred to publicly available data in the diagnostic waiting times and activity and/or the diagnostic imaging dataset which they did not have capacity to analyse.

However, the publicly available data from national datasets (which CCGs signposted Incisive to) do not provide all of the information requested by the survey. For example, X-ray data is provided in the diagnostic imaging dataset and diagnostic waiting times activity dataset but by provider rather than CCG, and on a quarterly basis. Histopathology is collected in the diagnostic waiting times and activity dataset, but only quarterly and not for all CCGs.

Examples of responses by CCGs when asked for activity and waiting times data

"The CCG does not routinely hold and/or measure data on average waiting times."

"Data is not collected at this level."

"There is insufficient data held." (for both activity and waiting times)

"[Activity] data is only collected for [one] local trust with 80% of the CCG secondary care activity."

The survey not only revealed gaps in data held by commissioners, but also discrepancies. Every CCG that provided data about diagnostic activity had different figures for certain tests to figures contained in the national data. The differences were generally small. However, some were significant: data contained in the diagnostic waiting times and activity dataset show that one CCG had undertaken 27,759 CT scans in 2016/17, but that CCG's response to our survey said that it had only undertaken 15,864. It is unlikely that this discrepancy can be

attributed to minor technical differences in reporting, but could be due to larger data reporting issues, or possibly how CCGs interpreted the survey question.

The CCGs that participated in the interviews could not explain why the survey found discrepancies between activity levels reported locally and those in nationally available data sets. However, one CCG said that nationally available data could be poor, unreliable, and "often quite out of date". Concerns were also raised that data on diagnostic activity does not differentiate between cancer and non-cancer tests, and that this can lead to planning issues and can affect the accuracy of commissioning decisions.

CCGs have a statutory duty to commission services to meet the needs of their local population.⁵⁶ Without this accurate and easily accessible information about local services, it is unlikely that CCGs will be able to evaluate the impact of the additional resources that they have been allocated to fund extra diagnostic activity. CCGs have stated they will monitor using performance reports, meetings with providers and with support from their local Commissioning Support Unit – this is covered further on page 30.

In addition to this, NHS planning guidance stipulated that in 2017/18, CCGs should ensure there is sufficient capacity to ensure 85% of patients continue to meet the 62 day standard by identifying any capacity gaps and then improving productivity or implementing plans to close them.⁵⁷ It is unlikely that commissioners will be able to do this without clear information about diagnostic activity levels.

Funding

The *Five Year Forward View* estimated a 7% increase in overall diagnostic activity year on year by the end of the decade.⁵⁸ NHS England confirmed that extra resources would be allocated as part of overall CCG funding allocations to enable CCGs to meet this increase in demand. To explore the extent to which this increase in funding is being spent on tests relevant to cancer, we asked CCGs to provide information on their budget allocation to fund imaging, pathology and endoscopy for the last four financial years and the projected spend for 2017/18.

Around half of respondents (59) were able to provide some information on budget allocations, but only 26% held the information requested in full. CCGs that were unable to respond to the question stated that they either did not set budgets at this level or did not hold financial information with this level of detail. The CCG interviews showed a similarly mixed picture: one CCG was unable to answer any general questions on resourcing, whereas the others showed clear understanding of their budgets.

Given the extra resource that has been allocated centrally to fund increases in diagnostic activity, it is important that local areas are able to account for how it is being spent – and to ensure it is being spent in the right places. This is particularly important given the current pressures on NHS finances. Despite the additional money allocated to the CCG baseline, of the CCGs that provided figures for imaging, pathology and endoscopy in 2015/16 and 2016/17, 29% (7) reported a decrease in the budget allocation between these years, including one CCG that decreased its total budget allocation by £2,359,801. It is interesting to note that most of these CCGs (6 out of 7) experienced higher volumes of activity in 2016/17 and/or

were expecting to see activity increase in 2017/18:

- One CCG reduced its planned budget allocation for imaging by £178,520 from 2015/16 to 2016/17, despite imaging activity for ultrasound, CT and MRI rising by 6,419 tests in total in the same period. Waiting times for imaging also rose during this period.
- One CCG reduced its planned budget allocation for ultrasound, CT and MRI from 2013/14 to 2016/17, even though total activity rose by over 7.5% in the same years.
- One CCG shared plans to decrease its budget allocation for imaging from 2016/17 to 2017/18 by £1,664,048. It was unable to provide projections of diagnostic activity, calling into question whether an impact assessment of the reduction in budget allocation had been undertaken.
- One CCG reduced its budget allocation for imaging by nearly £1 million (£959,488) from 2013/14 to 2016/17, despite activity rising by 3,065. This CCG stated that it had no plans to improve or expand diagnostic capacity in 2017/18 and had not made an assessment of the projected changes in demand.

CCGs that participated in the interviews could not offer an explanation as to why some CCGs appeared to be reducing their planned budget allocation for diagnostics. However, it is important to note that any reduction in budget allocation could be explained by changes in the way CCGs commission diagnostic services. For instance, a consolidation of services, the release of efficiency savings or purchasing of less expensive tests. These could be achieved when a CCG and a provider negotiate to achieve better value for money.

The findings from the survey do also raise questions about the quality of the data held and reported by some CCGs. For instance, of the CCGs that responded to the survey, only 24 provided budget allocation figures for imaging, pathology and endoscopy for the years 2015/16 and 2016/17. Even with these caveats, reductions in planned budget allocations for diagnostics are very concerning at a time when activity should be increasing.

Figure 12 shows how budget allocations changed from 2015/16 to 2016/17 for respondents that provided figures for these years. There was wide variation between CCGs, with one allocating 69% more in 2016/17 than in 2015/16, whilst another allocated 18% less in the same period. It is not clear whether the scale of this variation is due to data or financial reporting issues. It also does not show if these changes were correcting a historical over or under spend.

Some CCGs decreased one or all of their budget allocations for imaging, endoscopy and pathology without providing any data to indicate that an assessment had taken place of how changes in activity in these years that would warrant a re-prioritisation of funding.

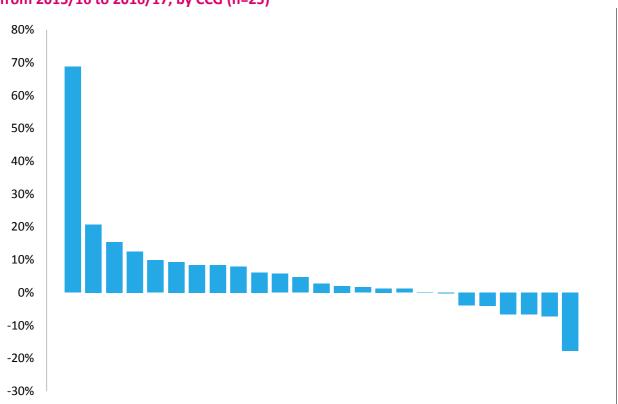


Figure 12: Percentage change in budget allocation on pathology, imaging and endoscopy from 2015/16 to 2016/17, by CCG (n=25)

Source: Incisive Health survey of CCGs

There are also wide variations in the level of budget allocated to tests. Figure 13 shows the budget allocation per capita for the 25 CCGs that provided figures for pathology, imaging and endoscopy in 2016/17. The chart shows wide variation between CCGs on how much they allocate per person, ranging from £19 to £61.

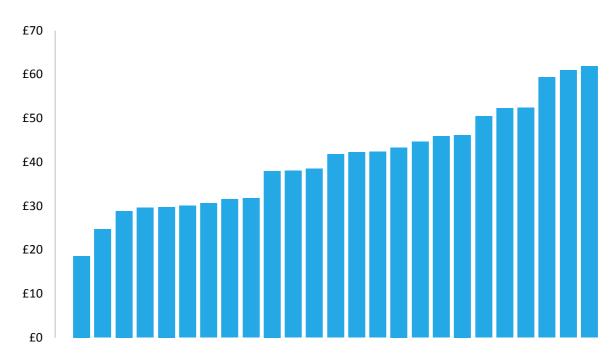


Figure 13: Total budget allocation per capita on pathology, imaging and endoscopy, 2016/17, by CCG (n=25)

Source: Incisive Health survey of CCGs

Only 13 CCGs provided budget allocation forecasts for 2017/18. Of these, most CCGs had planned to increase allocations or had planned to decrease budget allocation in one area due to corresponding lower activity in 2016/17. However, some had unexplained decreases:

- As noted previously, one CCG is planning to reduce its budget allocation for imaging by over £1 million, despite the average waiting time for tests going up in 2016/17. It is not clear whether this reduction was a part of an internal programme to improve the productivity and efficiency of services
- Another CCG is forecasting reduced allocation for imaging by over £450,000, but did not provide data on activity and stated that it had no plans to improve diagnostic capacity in 2017/18

Insights on funding that were raised during the CCG interviews may help to explain these findings. The interview participants raised concerns that money from the increase in the baseline allocation to fund diagnostics was being diverted to plug gaps in NHS finances, leaving them unable to invest in improving pathways or capacity due to funding constraints. One interview participant reported that funding pressures were so great that it felt like their CCG had not received the uplift in funding at all. Concerns were also raised that money for diagnostics was not reaching departments facing the greatest pressures. Worryingly, one CCG reported that a consultant had asked them to reduce the number of referrals to his department, because although they were performing more tests, the associated income was being spent elsewhere.

Planning for future demand

Projections of increased 7% demand for diagnostics were established through the Five Year Forward View modelling. But it is important to note this level of increase may not be sufficient to meet increased demand for suspected cancer and improving earlier diagnosis. NHS England has made it clear that it will provide additional resources through CCG baseline funding to meet this, stating that "CCG baseline allocations [in 2015/16] reflected a modelled increase in diagnostic capacity" to mitigate the significant challenges to improving earlier diagnosis. It is therefore important that commissioners can demonstrate that they are planning for changes in demand. In addition, CCGs should be aware that NHS planning guidance states that in 2017/18, CCGs must close gaps in diagnostic capacity by either implementing plans to close them or by improving productivity. ⁶⁰

CCGs were asked about their plans to improve and expand diagnostic capacity in 2017/18. Around 40% (38) of responding CCGs could not provide information on plans to improve or expand diagnostic services. Out of these, 26 said they had no plans to increase capacity in this financial year.

The remaining CCGs either did not provide an answer or said they did not hold the relevant information. Responses to the survey suggest that most CCGs are unable to provide detailed information about how they will monitor changes in demand and activity. 81% of CCGs (86) stated that they assessed changes in demand and monitored performance, but just over half of these (46) did not provide the activity or waiting time data that would support this, with most just referring to the diagnostic waiting times and activity dataset.

Those CCGs that did provide information used a range of techniques to anticipate changes in demand, including:

- Modelling in line with demographic growth
- Modelling using previous outturn data (ie the actual activity delivered for the whole financial year)
- Examining existing demand and capacity
- Developing new pathways and considering historic activity

Monitoring is typically done on monthly basis, using a range of techniques such as:

- Performance reports
- Meetings with contract providers
- Monitoring by the Commissioning Support Unit

Only one CCG provided details of monitoring capacity for individual tests.

Examples of approaches to demand planning:

"We have reviewed our historic demand and requests. As a result we have planned for a further 10% growth in endoscopy and a further 5% growth in imaging other than X ray where our demand is pretty flat"

"MRI – 9.1% - 370 mins more a week of capacity. CT- 9.7% - 14 mins more a week of capacity. Ultrasound – 5.7% - 949 mins more a week of capacity. Endoscopy – 6.9% annual growth. Gastroscopy - an additional 2000 patients per year within the next 4 years to meet the national anticipated growth rate and it is anticipated there will be 257 patients per week referred into the service"

There are some examples of CCGs playing an active role in designing new approaches to streamline diagnostic pathways, improve productivity and enable significant increases in activity. One CCG has taken steps to improve capacity for endoscopy, including introducing a telephone reminder system to reduce the number of Do Not Attends (DNAs), resulting in a drop in the DNA rate from 11% to 4% after four months. The CCG has also started overbooking weekday clinics in line with the DNA rate to help to maintain performance on the six-week waiting time standard.

Another CCG stated that it has introduced a direct pathway to test clinics for endoscopy, urology, radiology, as well as GP direct access to tests for pathology and radiology prior to referral for appointment.

Given that two thirds of responding CCGs (26) said they had no plans to increase capacity in this financial year, it was reassuring that all participants in the CCG interviews were able to share their plans for making improvements:

- To address the problem of wasted capacity from patients not attending appointments, one CCG is aiming to improve patient engagement by assigning patient navigators to guide patients through the process and provide support. The particular focus of this is for endoscopies, which had a 20-25% DNA rate within the CCG
- One CCG has responded to rising demand for tests under the two-week urgent referral
 pathway by procuring community providers for direct access, non-cancer endoscopy and
 ultrasound tests, to free up capacity in acute trusts specifically for cancer pathways
- One CCG is a pilot site for Cancer Research UK's Accelerate, Coordinate, Evaluate (ACE)
 Programme, and as part of the programme has established a 'block of tests' aligned to
 NICE guidance. This has meant that patients are more likely to receive the correct test
 straight away, which has led to less repeat testing and fewer tests being performed
 overall

National Diagnostics Capacity Fund

In May 2016 NHS England announced "£15 million in a new National Diagnostics Capacity Fund to explore new and innovative ways to deliver diagnostic services". 61 NHS England stated in the one-year on progress report on the cancer strategy that thirty projects have been approved for funding from this. 62 Only 13 responding CCGs (12%) were able to confirm that

they had received resources from the Fund, worth a total of £1.77m. The largest sum received by a CCG was £432,000.

Some CCGs were able to provide specific information on what the diagnostic capacity funding has been used for, including:

- Head and neck diagnostics
- Template biopsy (used to diagnose prostate cancer)
- Colorectal 'straight to test' pathway (enabling patients to go straight from a GP referral to a test, without requiring an outpatient appointment in-between)

There has not been publication of the Diagnostics Capacity Fund evaluation, although the NHS England one-year progress report stated the projects would be evaluated 'for efficacy' and successful models shared with Alliances.⁶³

Referral management schemes

Some CCGs have sought to review referrals to hospitals by GPs through the use of referral management programmes, which effectively provide an additional review of clinical decision-making.

An investigation by the *British Medical Journal* found that nearly four in ten (39%) of CCGs make use of some form of referral management scheme.⁶⁴ There have also been more recent investigations by Pulse which show that some areas are apparently including cancer in their schemes.⁶⁵ Most CCGs who responded to our survey confirmed that their schemes did not cover cancer, with explicit exemptions for the urgent referral pathway for suspected cancer.

However, four CCGs indicated that they did operate a referral management scheme for suspected cancer. In addition, two CCGs provided details of the specialities included in their scheme. One used the centres for bone, brain, breast, colorectal, gynaecology haematology and head and neck, while the other used them for gastroenterology, dermatology and gynaecology. They were not clear whether the remit of these specialities includes suspected cancers.

Referral management schemes can sometimes be used to ensure patients are being referred to the right place. However, any process which introduces delay or undermines GPs' referral intentions is concerning as it could lead to cancer being diagnosed less quickly and has implications for patient experience. The principle of referral management would also seem to run counter to the spirit of the NICE guidelines, which is to lower the threshold of suspicion for investigation, resulting in an increase in the number of tests conducted and referrals made for suspected cancer.

7 ENSURING THAT COMMISSIONERS DELIVER ON THE CANCER STRATEGY COMMITMENTS

The Independent Cancer Taskforce was clear that CCGs would need to play a key role in commissioning for improved cancer outcomes. The responsibilities of CCGs span the entire cancer pathway, from aspects of prevention to some treatment services, follow up and recovery and rehabilitation. However, a key responsibility is in relation to earlier diagnosis, ensuring that the resources are available to enable the increase in diagnostic activity that will be required to support a more proactive approach towards investigating potential cancer.

As a result of the cancer strategy, the Department of Health, NHS England and others have introduced a number of measures to support CCGs, including:⁶⁶

- Establishing cancer alliances to lead implementation of the cancer strategy locally
- Creating the National Cancer Diagnostics Fund to support increases in capacity
- Incorporating cancer indicators in the CCG Improvement and Assessment Framework
- Launching the Cancer Dashboard to provide ready access to key performance indicators
- Committing Transformation Funding to alliances to support efforts in diagnosing cancer earlier

However, there are significant gaps in intelligence about how CCGs are responding to the cancer strategy. For example, the National Cancer Advisory Group noted that:

"[Although] CCGs have received additional funding during 2016/17 to address diagnostics, reflecting a 7% predicted growth in activity...there is no means for the National Cancer Team to assess whether this funding is being spent to tackle capacity deficits."⁶⁷

The findings of this report suggest that the way in which CCGs have used additional funding has been patchy at best and that further levers are now required if the aspirations of the cancer strategy – to which the NHS and Government have committed – are to be realised.

As previously noted, parallels with recent commitments to increase mental health spending means that similar solutions could be adopted. In the 2018/19 planning guidance,

"Additional funding has now been built into CCG 2018/19 allocations to support the **expansion of services** outlined in this planning guidance and the specific trajectories set for 2018/19 to deliver the Five Year Forward View for Mental Health...

Each CCG must meet the **Mental Health Investment Standard** (MHIS) by which their 2018/19 investment in mental health rises at a faster rate than their overall programme funding. CCGs' auditors will be required to validate their 2018/19 year-end position on meeting the MHIS."68

This chapter sets a series of recommendations designed to ensure that the required increase in diagnostic capacity is appropriately planned for, funded, delivered and evaluated. The analysis contained in this report is based on data from England and the recommendations made are therefore directed at the NHS in England. However, some of the conclusions and recommendations may also apply to Scotland, Wales and Northern Ireland. There may be a case for similar analyses to be conducted in these nations.

RECOMMENDATIONS

Based on the findings in this report, we make a series of recommendations to ensure that additional resources are devoted to diagnostic capacity. These should be allocated as originally intended. Data should improve for the planning, delivery and accountability for diagnostic tests relevant to cancer.

Cancer Alliances should:

- Work with CCGs, STPs and providers to undertake a review of current and future diagnostic activity relevant to cancer.
- Identify within their Alliance any significant variations in activity between CCGs, investigate the reasons, and agree a published action plan to address any unwarranted variation.
- Review the commissioning of referral pathways to ensure they meet national guidance, such as the NICE recognition and referral guidance for suspected cancer or the National Optimal Lung Cancer Pathway.
- Highlight where future demand may exceed capacity to inform national funding and workforce plans.
- Share their diagnostic activity forecasts with Local Education and Training Boards (LETB) and Local Workforce Action Boards (LWABs) to inform local workforce plans.
- Explain where and why CCGs have not met the 7% increase in activity.
- Audit the impact that referral management centres have on cancer diagnoses and take corrective action if necessary.

NHS England (including the National Cancer Programme and Directors of Commissioning Operations) should:

- Publish an update to demonstrate progress made on increasing diagnostic capacity.
- Use CCG and alliance analyses to hold CCGs to account on meeting planning guidance.
- Make it clear (alongside NHS Improvement) that increases in diagnostic activity should not be compromised by the new Capped Expenditure Process. The financial processes required to implement the Capped Expenditure Process should be considered as a means of ensuring that funding is deployed for the purpose that it was initially allocated, as well as to control overall costs.
- The use of additional funding for diagnostics could be monitored using a similar system to the Mental Health Investment Standard⁶⁹, set out in 2018/19 NHS planning guidance. This says that CCGs' auditors will evaluate their 2018/19 year-end position to show investment has risen at a faster rate than overall programme funding.

Health Education England should:

 Use information from CCGs and alliances on their workforce needs to inform national action, such as increasing training places or coordinating post-graduate training.

The Department of Health should:

- Ensure that funding for diagnostic capacity is sufficient to meet future demand, and if
 not, increase and ring-fence this additional funding so it can be clearly demonstrated
 that it has been used for its intended purpose. This was a Government commitment so
 requires oversight from DH.
- Reassess capital investment requirements for diagnostics and consider the case for further investment to support increases in activity. This is timely in the context of the Department of Health's intention to develop a new capital strategy and the Government's manifesto commitment to "introduce the most ambitious programme of investment in buildings and technology the NHS has ever seen."

NHS Digital should:

- Improve diagnostic datasets so that the purpose and finding of an investigation is recorded, as well as the test that is undertaken. New national datasets should be implemented to record activity for endoscopy and pathology, to enable effective planning and commissioning of services. This is building on existing work to create a national endoscopy database and similar work on pathology.
- Work with CCGs to understand why some discrepancies occur between the figures in nationally reported data and locally held information on diagnostic activity and ascertain the true picture.

CONCLUSION

We welcome efforts from the Government and the NHS to diagnose cancer earlier – but these can be improved further with more scrutiny on how additional resources are deployed. The additional resources to boost diagnostic capacity should be used as originally intended. Increasing diagnostic capacity underpins all efforts to diagnose a greater proportion of people at an earlier stage. More diagnostic staff and kit means that initiatives like Be Clear on Cancer, NICE's NG12 referral guidance, the 28-day Faster Diagnosis Standard and improvements to bowel and cervical screening have a better chance of success. And in future, better data should improve the planning, delivery and accountability for diagnostic tests relevant to cancer.

8 ANNEX A: METHODOLOGY

Investigation for cancer can take many forms, including imaging, endoscopy and pathology. For ease, unless a specific form of diagnostic is being referred to, this report describes all such investigations as 'tests'.

Efforts to track cancer diagnostic activity and manage capacity have been frustrated by the absence of information on why tests were requested. It is therefore not possible to state whether a test was used to investigate symptoms of cancer or some other form of ill health. This matters because many tests are used for multiple purposes. For example, endoscopy can be used to investigate symptoms which might be colorectal cancer, but also other forms of bowel disease, such as Crohn's or colitis. Tests are also not just used for the initial diagnosis of cancer. They may be used post-diagnosis for surveillance, staging and the management of treatment.

This report therefore analyses data relating to diagnostic tests which are relevant to cancer – ie those which are frequently used to investigate cancer symptoms and for which investigations for cancer are believed to constitute a significant part of overall activity.

This report has used three main approaches to gathering information:

- 1. Synthesising information collected in publically-available datasets and analysing it to identify variations and trends
- 2. Surveying CCGs about their commissioning plans for diagnostics
- 3. Interviewing commissioners to understand local variations and the rationale behind commissioning decisions

This annex summarises the datasets used in developing this report, as well as the analytical approach adopted. It also explains some of the limitations in the analysis.

Data from existing sources on diagnostic waiting times and activity

Three publically-available datasets were used for this report and are listed below. The data included in this report have been analysed and presented by financial year. Each data set and the timeframes used are explored in turn below.

1. NHS England's diagnostic waiting times and activity dataset

Diagnostic waiting times and activity dataset provides data on waiting times and activity for 15 tests and procedures.⁷¹ It has been published each month by NHS England since 2008 and includes information at a CCG level on:

 The number and percentage of patients waiting six weeks or longer for a diagnostic test, from time of referral Current waiting times of patients still waiting for any 15 key diagnostic tests or procedures at the month end

National data available for 2008/09 to 2016/17 (data for 2016/17 was provisional at the time of writing)

- CCG-level data available for 2013/14 to 2016/17
- National data available for 2008/09 to 2016/17

2. NHS Digital's Diagnostic Imaging Dataset

Diagnostic Imaging Dataset provides detailed information about diagnostic imaging tests that are carried out on NHS patients.⁷² It is published monthly at the provider level, containing information on the number of all diagnostic imaging tests carried out on NHS patients. It also includes information on:

- Referral source and patient type (eg inpatient, outpatient, A&E patient)
- Details of the test (type of test and body site)
- Demographic information such as GP registered practice, patient postcode, ethnicity, gender and date of birth
- Items about waiting times for each diagnostic imaging event, from time of test request through to time of reporting
 - Trust and national data available for 2012/13 to 2015/16 (at time of writing)

3. Atlas of Variation in NHS Diagnostic Services

The Atlas of Variation in NHS Diagnostic Services brings together information on geographical variation in diagnostic testing, including indicators on endoscopy⁷³

National data available for 2005/06 to 2014/15

It should be noted that that from April 2012/13, diagnostic imaging in the outpatient setting was "unbundled" in NHS England's National Tariff, which disaggregated the cost of a diagnostic test from the cost of the single outpatient payment that was made prior to this date.

Diagnostics analysed

The following diagnostics were analysed in this report:

- Barium enema a test that helps to highlight the large bowel, so it can be clearly seen on an x-ray, used to diagnose bowel cancer (although it is no longer deemed clinically appropriate)
- **Colonoscopy** a procedure where a flexible tube with a camera is inserted to look inside the bowel and remove small growths called polyps

- **Computed tomography (CT)** a scan that uses x-rays to create detailed images of the inside of the body
- Cystoscopy a procedure where a flexible tube is inserted through the urethra to look inside the bladder
- **Flexible sigmoidoscopy** a procedure where a flexible tube is inserted look inside the lower part of the large bowel
- **Fluoroscopy** a continuous X-ray beam used to create real-time moving images of specific areas of the body, including bones, muscles, joints, and organs such as the heart, lung, or kidneys
- **Gastroscopy** a procedure where a flexible tube is used to look inside the oesophagus, stomach and first part of the small intestine
- Magnetic resonance imaging (MRI) a scan that uses magnetic fields and radio waves to produce detailed images of the inside of the body
- Medical photography specialised photography, predominately used to diagnose skin cancer
- **Non-obstetric ultrasound** a procedure that uses high-frequency sound waves to create an image of part of the inside of the body, in a context other than pregnancy
- **Nuclear medicine** procedures that involve the use of radioactive substances to diagnose various cancers, including brain, breast, kidney, bladder, liver, lung and bone cancers
- **Positron Emission Tomography (PET scan)** an imaging test that uses dye with radioactive tracers, used to determine whether a tumour is cancerous
- **Single photon emission CT (SPECT)** an imaging technique using gamma rays, most commonly used to diagnose cancer that has spread to the bones
- **Urodynamics** a test that assesses bladder and urethra function, to exclude non-cancerous causes of lower urinary tract symptoms
- **X-ray** a test used to create images of the body, used to diagnose a range of cancers including lung cancer, bone cancer and to see if a cancer has spread

The majority of these tests are commissioned by CCGs. However, the PET scan is commissioned centrally by NHS England through its specialised commissioning function. This test is therefore excluded from CCG-level analysis.

In order to enable year on year analysis, monthly data were aggregated for each financial year and the arithmetic mean was calculated for the number of patients waiting more than six weeks at the end of each month in that financial year.

Per capita analysis has been used when analysing data by CCG. This is to ensure variations in activity can be explained, analysed or reported after differences in the size of the population have been taken into account.

Where per capita figures have been provided for expenditure and number of tests, these have been calculated by dividing the expenditure/number of tests by the population of England or each CCG using population estimates from the Office of National Statistics for that year. 2016/17 per capita figures have been calculated using 2015 mid-year population estimates, as these are the most recent estimates available.

CCG survey

CCGs were sent a short survey in April, with responses requested by May. The survey investigated the following issues:

- CCG understanding of changes in diagnostic activity and waiting times
- Allocations of funding to increase capacity and productivity of diagnostic services
- Commissioning plans in 2017/18 to monitor improvements in diagnostic services and capacity
- The existence of referral management centres to assess referrals by local GPs

The survey questions were as follows:

- 1. Please confirm how many of the following diagnostic tests have been carried out in your area in each financial year since April 2013: (a) x-ray; (b) ultrasound; (c) CT scan; (d) MRI scan; (e) gastroscopy; (f) colonoscopy; (g) flexible sigmoidoscopy; and (h) histopathology.
- 2. Please confirm what the average waiting time in your CCG was for the following tests in each financial year since April 2013: (a) x-ray; (b) ultrasound; (c) CT scan; (d) MRI scan; (e) gastroscopy; (f) colonoscopy; (g) flexible sigmoidoscopy; and (h) histopathology.
- 3. Please confirm your CCG's budget allocation to fund imaging, pathology and endoscopy activity in each financial year since April 2013, and what it is forecast to be in 2017/18.
- 4. Please confirm whether your CCG received additional funding from the National Diagnostics Capacity Fund to increase capacity and productivity of diagnostic services. If so, how much.
- 5. Please confirm how your CCG assesses anticipated changes in demand for (a) x-ray; (b) ultrasound; (c) CT scan; (d) MRI scan; (e) gastroscopy; (f) colonoscopy; (g) flexible sigmoidoscopy; and (h) histopathology, and what assessment it has made of projected changes in demand.
- 6. Please confirm whether your CCG has plans to improve and expand diagnostic capacity in 2017/18 and, if so, what those plans are.
- 7. Please confirm how your CCG monitors capacity and performance for (a) x-ray; (b) ultrasound; (c) CT scan; (d) MRI scan; (e) gastroscopy; (f) colonoscopy; (g) flexible sigmoidoscopy; and (h) histopathology.
- 8. If diagnostic capacity has not been subject to increased investment, which of the 9 'must dos' from the 2016/17 NHS England planning guidance have been prioritised?
- 9. Please confirm whether your CCG operates or commissions a referral management centre that assesses referrals by local GPs.

10. If yes to question nine, please confirm whether the list of specialities that fall under the referral management centre's remit include suspected cancer cases.

The full text of the survey is included in Annex B.

In total, 106 CCGs provided a response to the survey between April and July, representing a response rate of just under 50%. We are grateful to the CCGs which took the time to respond. In order to encourage CCGs to respond to future surveys and to encourage candour, evidence from the survey has been anonymised.

Follow up interviews

Initial analysis of datasets and the responses to the survey of CCGs highlighted unexplained variations in the level of diagnostic activity, commissioning behaviour and the quality of data recorded. In order to understand this variation, follow up interviews were carried out with representatives from four CCGs to explore how and why commissioners are approaching cancer diagnostics in the way they are.

Semi-structured telephone interviews were carried out and covered the following issues:

Prioritisation of cancer

- How much of your time is spent on cancer issues? Of this, how much of your time is spent on diagnostics?
- Has the prioritisation given to cancer diagnostics changed in recent years?
- How do you track your progress in implementing the Cancer Strategy?

Predicting demand

- How do you set about predicting the demand for cancer diagnostics? What factors do you take into account?
- Have you sought to assess how your diagnostic activity compares to other CCGs? How did you do this?
- Has demand for cancer diagnostics changed in recent years? How does this compare to other forms of activity?

Resourcing demand

- How has your expenditure changed on cancer diagnostics?
- Does it feel as though you are receiving more resources? If so, how much?
- What is happening to the cost of diagnostic activity? Are individual tests reducing in cost?

Overcoming challenges

 What are the biggest challenges you face in your role as commissioners of cancer diagnostics?

- What could NHS England most usefully do to support you?
- How would you like to work with your STP / Cancer Alliance?

Interviewees and comments made during the interviews have been kept anonymous. However, feedback from the discussions has been incorporated into the report and we are grateful to commissioners for taking the time to speak with us.

Limitations

As with any study, there are limitations to the analysis presented in this report. These include:

- There may be inconsistencies with information reported by NHS organisations
- Data on diagnostic tests are not specific to tests requested to investigate suspected cancer, and so includes information on activity relating to other conditions
- Diagnostic tests are not just limited to diagnosis of cancer, but are also used for management, surveillance and more accurate staging
- It is not possible to ascertain what each test found or whether it was an appropriate investigation for the symptoms displayed by the patient
- It is not possible to ascertain from national data why changes in activity occurred
- The survey provides a partial picture of CCG behaviour as the response rate was less than 50%. Some CCGs may not have responded to the survey due to time pressures or a lack of capacity to analyse the relevant data

Finally, this survey only examined diagnostic activity. Although there is good evidence that an earlier diagnosis of cancer increases the chances of a positive outcome from treatment, it is not yet possible to analyse the impact that changes in diagnostic activity have on cancer survival. However, being able to deliver sufficient diagnostic tests is crucial — without sufficient capacity, efforts and interventions to diagnose people earlier are likely to be undermined and worse, avoided, in future.

Nonetheless, the findings presented in this report provide an insight into the progress the NHS is making to increase investigations for potential cancer and the extent to which resources are being used at a local level for the purpose they were intended.

9 ANNEX B: SURVEY ON DIAGNOSTICS ACTIVITY, PLANNING AND FUNDING

The following text was sent to all CCGs as part of the survey:

Dear CCG colleague,

On behalf of Cancer Research UK, we are conducting a survey about diagnostic testing activity, planning and funding. The survey opens on Monday 10 April and closes on Monday 15 May 2017.

We have a number of questions, which are as follows:

Activity and waiting times

- 1. Please confirm how many of the following diagnostic tests have been carried out in your area in each financial year since April 2013: (a) x-ray; (b) ultrasound; (c) CT scan; (d) MRI scan; (e) gastroscopy; (f) colonoscopy; (g) flexible sigmoidoscopy; and (h) histopathology.
- 2. Please confirm what the average waiting time in your CCG was for the following tests in each financial year since April 2013: (a) x-ray; (b) ultrasound; (c) CT scan; (d) MRI scan; (e) gastroscopy; (f) colonoscopy; (g) flexible sigmoidoscopy; and (h) histopathology.

Funding

- 3. Please confirm your CCG's budget allocation to fund imaging, pathology and endoscopy activity in each financial year since April 2013, and what it is forecast to be in 2017/18.
- 4. Please confirm whether your CCG received additional funding from the National Diagnostics Capacity Fund to increase capacity and productivity of diagnostic services. If so, how much.

Plans to invest and monitoring

- 5. Please confirm how your CCG assesses anticipated changes in demand for (a) x-ray; (b) ultrasound; (c) CT scan; (d) MRI scan; (e) gastroscopy; (f) colonoscopy; (g) flexible sigmoidoscopy; and (h) histopathology, and what assessment it has made of projected changes in demand.
- 6. Please confirm whether your CCG has plans to improve and expand diagnostic capacity in 2017/18 and, if so, what those plans are.

- 7. Please confirm how your CCG monitors capacity and performance for (a) x-ray; (b) ultrasound; (c) CT scan; (d) MRI scan; (e) gastroscopy; (f) colonoscopy; (g) flexible sigmoidoscopy; and (h) histopathology.
- 8. If diagnostic capacity has not been subject to increased investment, which of the 9 'must dos' from the 2016/17 NHS England planning guidance have been prioritised?

Referral management centre

- 9. Please confirm whether your CCG operates or commissions a referral management centre that assesses referrals by local GPs.
- 10. If yes to question nine, please confirm whether the list of specialities that fall under the referral management centre's remit include suspected cancer cases.

I wish to receive the information requested via email.

Yours sincerely

10 GLOSSARY

- **Barium enema** a test that helps to highlight the large bowel, so it can be clearly seen on an x-ray (soon to be discontinued)
- Cancer Alliances 16 alliances, have been set up across England to lead on local planning and delivery of the cancer strategy with a whole-pathway and cross-organisational approach
- Cancer Dashboard an online dashboard co-produced by NHS England and Public Health
 England that brings together data across the whole cancer pathway at CCG, provider and
 national levels.
- Capped Expenditure Process a process which aims to contain or cap spending in 14 areas of the country with particular financial challenges
- CCG Improvement and Assessment Framework a framework with performance indicators by which NHS England conducts an annual assessment of every CCG
- **Colonoscopy** a procedure where a flexible tube with a camera is used to look inside the bowel (and can remove small growths called polyps)
- Commissioning the process by which services are planned, organised and contracted
- **Computerised tomography (CT)** a scan that uses x-rays and a computer to create detailed images of the inside of the body
- **Cystoscopy** a procedure where a flexible tube is inserted through the urethra to look inside the bladder
- Diagnosis the determination of the cause of a patient's illness or suffering by the
 combined use of physical examination, patient interview, laboratory tests, review of the
 patient's medical records, knowledge of the cause of observed signs and symptoms, and
 differential elimination of similar possible causes
- **Diagnostic activity** a count of the number of diagnostic tests undertaken
- **Diagnostic capacity** the staff, equipment and funding required to undertake diagnostic tests
- Diagnostic test a test or procedure of which the primary function is to identify a
 patient's disease or condition to allow a medical diagnosis to be made
- Endoscopy a flexible tube used to look inside a person's body, comprising tests such as

gastroscopy, colonoscopy, flexible sigmoidoscopy and cystoscopy

- **Flexible sigmoidoscopy** a procedure where a flexible tube is used to look inside the lower part of the large bowel
- Fluoroscopy a continuous X-ray beam used to create real-time moving images of specific areas of the body, including bones, muscles, joints, and organs such as the heart, lung, or kidneys
- **Gastroscopy** a procedure where a flexible tube is used to look inside the oesophagus, stomach and first part of the small intestine
- Magnetic resonance imaging (MRI) a scan that uses magnetic fields and radio waves to
 produce detailed images of the inside of the body
- Medical photography specialised photography, predominately used to diagnose skin cancer
- **Non-obstetric ultrasound** a procedure that uses high-frequency sound waves to create an image of part of the inside of the body, in a context other than pregnancy
- **Nuclear medicine** procedures that involve the use of radioactive substances to diagnose various cancers, including brain, breast, kidney, bladder, liver, lung and bone cancers
- Pathology diagnosis of disease based on the laboratory analysis of tissues or bodily fluids such as blood and urine
- **Positron Emission Tomography (PET scan)** an imaging test that uses dye with radioactive tracers, used to determine whether a tumour is cancerous
- **Single photon emission CT (SPECT)** an imaging technique using gamma rays, most commonly used to diagnose cancer that has spread to the bones
- Stage a way of describing the size of the cancer and how far it has grown
- **Urodynamics** a test that assesses bladder and urethra function, and diagnoses bladder cancer
- **X-ray** a test used to create images of the body, used to diagnose a range of cancers including lung cancer, bone cancer and to see if a cancer has spread

Publication date January 2018 Registered Charity in England and Wales (1089464), Scotland (SC041666) and the Isle of Man (1103)



http://www.cancerresearchuk.org/xxxxxxxxx

Cancer Research UK is the world's largest independent cancer charity dedicated to saving lives through research. It supports research into all aspects of cancer and this is achieved through the work of over 4,000 scientists, doctors and nurses. In 2016/17, we spent £432 million on research in institutes, hospitals and universities across the UK. We receive no funding from the Government for our research and are dependent on fundraising with the public. Cancer Research UK wants to accelerate progress so that three in four people survive their cancer for 10 years or more by 2034.

This project has been commissioned by the Cancer Research UK Policy Development team. It was written by Incisive Health and edited by Sara Bainbridge.

For more information, please contact policydepartment@cancer.org.uk

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